Engaging the public in priority setting for health in rural South Africa

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Declaration

I, Aviva Tugendhaft, declare that this Thesis is my own original work conducted under the supervision of Karen Hofman, Kathleen Kahn and Nicola Christofides. It is being submitted for the Degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.

Signed

3rd day of October 2023

Dedication

To the giants who came before me- my late mother Karin and my father Oshy- thank you for always encouraging academic pursuits

To the little giants who came after me- Elai and Kai- may this inspire you

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There are so many individuals who have played a role at some point during this PhD journey and to whom I am grateful:

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MY village- because it takes one, to raise a PhD.

Presentations arising from the work

Tugendhaft, A. *Science engagement to achieve equality and social justice – the case of CHAT.* Falling Walls, Engage, launch of South Africa Hub. Cape Town. November 2022

Tugendhaft A, Hofman K, Danis M, Kahn K, Erzse A, Twine R, Gold M, Christofides. *Deliberative engagement and health care priority-setting in a rural South African community* International Society for Priorities in Health Care (virtual). April 2022

Tugendhaft A, Erzse A, Danis M, Goldstein S, Hofman K *Public engagement achieving sustainable development in rural and urban South Africa.* Public Health Association of South Africa: 2022. Durban

Tugendhaft A, Hofman K, Erzse A, Christofides N, Kahn K, Danis M. *Engaging the public in priority setting for health*. Child Health Priorities Conference. Johannesburg: 2019

Tugendhaft A, Danis M, Christofides N, Kahn K, Erzse A, Gold M, Twine R, Khosa A, Hofman K. *CHAT SA: Engaging the public in priority setting for health in rural South Africa.* Wits School of Public Health Research Day: 2018

Tugendhaft A, Hofman K, Danin M, Gold M. *How can we engage the public in decisions about healthcare in South Africa International Society for Priorities in Health Care* Birmingham, 2016.

Publications arising from the work

This is a PhD thesis by publication. The following manuscripts have been published and the authors have provided permission for their use in this thesis:

- **Tugendhaft A,** Danis M, Christofides N, Kahn K, Erzse A, Gold M, Twine R, Khosa A, Hofman K. 2022. CHAT SA: Modification of a Public Engagement Tool for Priority Setting for a South African Rural Context, *International Journal of Health Policy and Management*, 11: 197-209. doi: 10.34172/ijhpm.2020.110
- **Tugendhaft A,** Hofman K, Danis M, Kahn K, Erzse A, Twine R, Gold M, Christofides N. 2021. Deliberative engagement methods on health care priority-setting in a rural South African community. *Health Policy Plan*, 36: 1279-91. doi: 10.1093/heapol/czab005
- **Tugendhaft A,** Christofides N, Stacey N, Kahn K, Erzse A, Danis M, Gold M, Hofman K. Moving towards social inclusion: Engaging rural voices in priority setting for health. *Under review at Health Expectations*

Other activities arising from this work

This work led to three other projects in Sub-Saharan Africa where the CHAT tool was modified for nutrition interventions for women and children during the first 1000 days. These projects are part of an NIHR funded research group and my inmvolvement included technical support to guide the adaptation and implementation of the CHAT tool for Soweto, South Africa, Navrongo, Ghana and Nanoro, Burkino Faso. My experience from my own work enabled me to provide support in terms of training of the research team in the adaptation and use of CHAT, guiding the material developments, and the data collection and analysis process. The projects are ongoing and to date one paper has been published:

Dalaba, M. A., Nonterah, E. A., Chatio, S. T., Adoctor, J. K., Dambayi, E., Nonterah, E. W., Azalia, S., Ayi-Bisah, D., Erzse, A., Watson, D., Hardy-Johnson, P., Kehoe, S. H., **Tugendhaft, A.,** Ward, K., Debpuur, C., Oduro, A., Ofosu, W., Danis, M., Barker, M., & INPreP study group (2022). Engaging community members in setting priorities for nutrition interventions in rural northern Ghana. *PLOS global public health*, *2*(9), e0000447. https://doi.org/10.1371/journal.pgph.0000447

Abstract

Introduction: The importance of public engagement in health priority setting is widely recognised as a means to promote more inclusive, fair, and legitimate decision-making processes. This is particularly critical in the context of Universal Health Coverage, where there is often an imbalance between the demands for and the available health resources. In South Africa, public engagement is protected in the Constitution and entrenched in policy documents; yet context specific tools and applications to enable this are lacking. Where public engagement initiatives do occur, marginalised voices are frequently excluded, and the process and outcomes of these initiatives are not fully evaluated. This hampers our understanding of public engagement approaches and how to meaningfully include important voices in the priority setting agenda. The aim of this doctoral (PhD) research was to investigate the feasibility and practicality of including the public in resource allocation and priority setting for health in a rural setting in South Africa using an adapted deliberative engagement tool called CHAT (Choosing All Together).

Methods: The PhD involved the modification and implementation of the CHAT tool with seven groups in a rural community in South Africa to determine priorities for a health services package. For the modification of CHAT, desktop review of published literature and policy documents was conducted, as well as three focus group discussions, with policy makers and implementers at national and local levels of the health system and the community, and modified Delphi method to identify health topics/issues and related interventions appropriate for a rural setting in South Africa. Cost information was drawn from various national sources and an existing actuarial model used in previous CHAT exercises was employed to create the board. The iterative participatory modification process was documented in detail.

The implementation process was analysed in terms of the negotiations that took place within the groups and what types of deliberations and engagement with trade-offs the participants faced when resources were constrained. In terms of the outcomes, the study focused on what priorities were most important to the rural community within a constrained budget and the values driving these priorities, but also how priorities might differ amongst individuals within the same community and the characteristics associated with these choices. Qualitative data were analysed from the seven group deliberations using the engagement tool. Content analysis was conducted, and inductive and deductive coding was used. Descriptive statistics was used to describe the study participants using the data from a demographic questionnaire and to show the group choices from the stickers allocated on the boards from the groups rounds. The investment level (sticker allocation) of all study participants was recorded at each stage of the study. From these the number of stickers allocated to each topic by the participants was calculated by adding up the number of stickers across interventions selected by the participant by topic. The median and interquartile range across study participants was calculated for the topic totals. To examine differences in sticker allocations, Wilcoxon rank sum tests were performed for differences across participant categories and sticker allocations in the final round of CHAT.

Findings: Based on the outcomes, seven areas of health need and related interventions specific for a rural community context were identified and costed for inclusion in the CHAT board. These include maternal, new-born and reproductive health; child health; woman and child abuse; HIV/AIDS and TB; lifestyle diseases; quality/access; and malaria. The CHAT SA board reflects both priority options of policymakers/ experts and of community members and demonstrates some of the context specific coverage decisions that will need to be made under NHI. The CHAT implementation shows that the rural communities mostly prioritised curative services over primary prevention due to perceived inefficacy of existing health education and prevention programmes. The exercise fostered strong debates and deliberations. Specifically, the groups engaged deeply with trade-offs between costly treatment for HIV/AIDS and those for non-communicable disease. Barriers to healthcare access were of particular concern and some priorities included investing in more mobile clinic. The individual level priorities were mostly aligned with societal ones, and there were no statistically significant differences between the individual and group choices. However, there were some statistically significant differences between individual priorities based on demographic characteristics such as age. The study demonstrates that giving individuals greater control and agency in designing health services packages can increase their participation in the priority setting process, align individual and community priorities, and enhance the legitimacy and acceptability of the decision-making process. In terms of reconciling plurality in priority setting for health, group deliberative approaches help to identify social values and reconcile some of the differences, but additional individual voices may also need to be considered alongside group processes, especially among the most vulnerable.

Conclusion: This research marks the first instance of modifying and implementing a deliberative tool for priority setting in a South African rural context. The findings shed light on the process and some of the outcomes of this approach within a vulnerable community, offering insights into public engagement in priority setting more broadly. The study demonstrates that participatory methods are feasible in modifying public engagement tools such as CHAT and can be adapted to different country contexts, potentially enhancing the priority setting process. Regarding the implementation of CHAT, the study provides an example of how a rural community grappled with resource allocation decisions, considered different perspectives and societal implications, and set priorities together. The research also highlights the priorities of this rural community, the social values driving their choices, and individual characteristics that are important to consider when setting priorities. The work demonstrates that meaningful public engagement includes various factors that interrelate and impact one another and that could inform a dynamic and cyclical approach going forward, as well as the importance of transparency during all stages of the process.

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List of abbreviations and acronyms

ARVs	Antiretrovirals
CAB	Community Advisory Board
CHAT	Choosing All Together
CHCs	Community Health Committees
DOH	Department of Health
FGD	Focus Group Discussion
HBC	Home Based Carer
HTA	Health Technology Assessment
HITAP	Health Intervention and Technology Assessment Programme
HIV/AIDS	Human immunodeficiency virus/acquired immunodeficiency syndrome
LMICS	Lower-middle-income settings
MNRH	Maternal, neonatal and reproductive health
NCDs	Non-communicable diseases
NCOP	National Council of Provinces
NDOH	National Department of Health
NHI	National Health Insurance
NICE	National Institute for Health Care Excellence
SA	South Africa
TB	Tuberculosis
UHC	Universal Health Coverage
UN	United Nations
WHO	World Health Organisation

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Organisation of the Thesis

My PhD is by publication using a block format. The block format includes a literature review and critical analysis and requires that the results sections comprise the published (or submitted) papers in their entirety. This thesis consists of eight chapters that are organised as follows:

Chapter 1 provides the introduction to the work. It includes my research statement and positioning of the PhD. The chapter describes priority setting for health and public engagement in priority setting for health. It explains the methods of public engagement and introduces the specific public engagement tool (Choosing All Together) that was used in my study. The South African context is described, and the chapter ends with the justification for the work and the research aims and objectives.

Chapter 2 includes the literature review. It describes the evolution of public engagement in priority setting for health on a global scale and in the South African context. The theoretical foundations and the practical applications of public engagement in priority setting for health are explored. The chapter concludes with an assessment of the gaps in the literature and an adapted conceptual framework that guided the work and could serve as a basis for meaningful public engagement in priority setting for health.

Chapter 3 describes the overall methodology for my doctoral research and the specific steps related to each objective as well as to the theoretical approach guiding the methods. It also demonstrates my positionality as a researcher and describes my level of involvement in the method design, data collection and analysis.

Chapters 4, 5 and 6 present the results of the PhD study. Each chapter follows a format of a journal article and provides background, methods, findings and discussion of findings.

Chapter 4 describers the modification process of a public engagement tool for a South African rural setting. The chapter includes the detail and outcome of an iterative participatory process for the modification of the Choosing All Together (CHAT) tool. Chapter 5 explores the group deliberation process and outcomes using CHAT to identify what issues were prioritised by community members, the reasons for these selections and how negotiations and engagements with trade-offs took place within the groups. Chapter 6 presents the results of the outcome of the individual process as compared to the group deliberation for priority setting for health and the characteristics that influence decisions at the individual level.

Chapter 7 is the discussion and presents key findings of my work in relation to the literature and the gaps that exist. The chapter demonstrates the contributions that the work makes to the public engagement field and considers the limitations.

Chapter 8 provides my conclusion and proposes recommendations for policy, practice and future research.

Chapter 1

1 Introduction

"The idea of citizen participation [or engagement] is a little like eating spinach: no one is against it in principle because it is good for you. Participation…is, in theory, the cornerstone of democracy-a revered idea that is vigorously applauded by virtually everyone. The applause is reduced to polite handclaps, however, when this principle is advocated by [or for] the have-not[s]…" (Arnstein, 1969).

This doctoral (PhD) thesis focuses on public engagement in priority setting for health in a rural setting in South Africa. This background chapter includes the research statement and positioning of the PhD, followed by conceptualisation/definition of some key terms. Subsequent sections of the background describe methods of public engagement and introduce the specific engagement tool that was used in this work. An overview of the research context is provided and finally, the justification for the study and the aims and objectives are described. The ultimate aspiration for this work is that it in some way contributes to moving beyond theoretical support to a better understanding of the practical application of public engagement in priority setting for health, especially among vulnerable populations.

1.1 Research statement and positioning of the PhD

This PhD thesis investigates the feasibility and practicality of including the public in resource allocation and priority setting for health in a rural setting in South Africa. It explores how community members engage with a context specific public deliberation tool, what decisions are made within a constrained budget using the tool, as well as the deliberations, justifications and characteristics that drive these decisions. Through this analysis the research aimed to develop an understanding of the process of a particular public engagement approach in a rural community as well as the outcome of using this approach and to demonstrate how marginalised voices may be meaningfully incorporated in the priority setting agenda. The work crosses the disciplines of public health, sociology, and political science, drawing on influences from bioethics, development studies and economics.

1.2 Priority setting for health

Priority setting for health refers to the process of determining what health services or interventions to fund or not to fund, in the context of demands on healthcare resources being greater than the resources available (Primary Care Trust Network, 2007). These decisions extend to how to deliver essential services, protect populations from the costs of ill health, and address health inequities (Powers, 2006 ; World Health Organisation, 2014). Historically, priority setting has often been ad-hoc or history based resulting in sub-optimal allocation of resources (Baltussen et al., 2016). Explicit priority setting, however, usually relies on the assessment of benefits and costs of health interventions according to pre-defined decision criteria and health economic methodologies such as cost effectiveness analyses (CEA) (Baltussen et al., 2016; Chalkidou et al., 2016; Weale et al., 2016). More recently, it has been accepted that priority setting is morally complex and multiple criteria beyond cost-effectiveness are important, as well as the consideration of social values (Baltussen et al., 2016; Sabik & Lie, 2008; Savedoff et al., 2012; Weale et al., 2016; World Health Organisation, 2014) As countries pursue Universal Health Coverage (UHC) these considerations are even more pertinent as questions arise not only about which health services and populations should be covered under national UHC schemes, but also about how these decisions should be made (Daniels, 2000).

1.3 Public engagement in priority setting for health

In this research, public engagement in priority setting for health refers to meaningful engagement where members of the public are actively involved in the decision-making activities for the development of health policies and services at local or national level (Florin

& Dixon, 2004). This differs significantly from passively involving the public through a top-down approach where information is simply communicated. The term public refers to "ordinary people with an emphasis on the inclusion of groups whose voices are marginalised in political processes and in daily life" (Blacksher, 2013). While there is overlap with patient engagement, the latter refers more specifically to "the involvement of individual patients, together with health professionals, in making decisions about their own health care" (Vahdat et al., 2014). Public engagement and public participation are often synonymous, but the former is sometimes considered to include more two-way communication (Blacksher, 2013; Mitton 2009). In this thesis engagement and participation are used interchangeable to refer to meaningful engagement as defined above.

There is increasing recognition of the importance of engaging the public in health decision-making, especially as countries move towards UHC and demands outweigh available resources. In the pursuit of UHC, decision-makers can benefit from public accountability, and public engagement can help guide ethical decisions on complicated health policy questions (Baltussen et al., 2016; Weale et al., 2016).

There are many justifications for public engagement in priority setting. The simplest of these is embedded within deliberative democracy theory and holds that there is an imperative to involve those whose lives are affected by a decision in its development (Abelson et al., 2003). This position further supports the idea that health priority setting should reflect the values of the people and meaningful public engagement can facilitate this (Abelson et al., 2013; Baltussen et al., 2016; Childress et al., 2002; Clark & Weale, 2012; Daniels, 2000; Mitton et al., 2009; Sibbald et al., 2009). These "social values" are the set of principles that are morally acceptable and endorsed by a particular society. They are created by the dynamics of the community, the institutions in the society, and the traditional and cultural beliefs of the people in the society (Weale, 2016). Distinct from individual values, social values contain a concern for others welfare. Beyond improving the ability of citizens to influence decisions on issues that affect their lives, public engagement has the potential to reinforce the legitimacy and the public acceptability of the decision-making process and its outcomes; increase the success rate of policy implementation; manage community expectations and improve public understanding of the issues considered (Scuffham et al., 2014).

While public engagement is widely endorsed, many questions remain about how best to achieve this goal and how effective engagement might be in producing fairer and more legitimate decisions (Abelson et al., 2013; Alderman et al., 2013; Carman et al., 2015a). Some of the cited limitations of engaging the public in healthcare priority decisions include concerns about the ability of members of the public to be objective and to represent societal interests. Other concerns are that members of the public cannot contribute meaningfully because they do not have enough knowledge about complicated aspects of healthcare or are unable to understand rationing of healthcare resources and the need for priority setting; and that there is reluctance on behalf of the public to be involved in the prioritisation process (Carpini et al., 2004; Meetoo, 2013). Further barriers include the concern that a small group of selected individuals might not be representative of the public and that involving the public will delay the decision-making process (Irvin & Stansbury, 2004). While all of these are potential limitations, advocates of public engagement concede that some limitations are overstated and can be avoided with the appropriate engagement methodology (Abelson, 2003).

1.4 Public engagement methods

Methods of engaging the public in priority setting fall broadly into non-deliberative and deliberative processes (Blacksher, 2013). Non-deliberative methods include surveys, discreet choice experiments, willingness to pay, feedback meetings among others, in which participants do not engage in person-to person dialogue or debate and where individual level preferences are usually aggregated (Baker et al., 2021; Gutmann & Thompson, 2004). These approaches may elicit some public values based on individual preferences but do not consider the quality of the underlying reasons (Solomon & Abelson, 2012). While these methods may be consultative in nature, they either do not provide the same degree of consideration, nor do they include the necessary two-way communication that deliberative methods offer. Some of these methods, however, do have a wider reach than deliberative approaches (Baker et al., 2021).

Deliberative methods involve deeper engagement and considerations of perspectives among a selected group of individuals and rely on group level deliberation to find collective solutions to social problems (Baker et al., 2021; Blacksher, 2013; Mitton et al., 2009). Deliberation does not always rely on consensus but on an agreed set of outputs that can inform decision making (Blacksher, 2013; Blacksher et al., 2012).

Deliberative public engagement has been proposed for priority setting, specifically where issues are complex and there are diverse public perspectives and low awareness of competing issues. This type of engagement is considered useful in identifying and balancing individual and societal values, beliefs and concerns and driving collective outputs (Abelson et al., 2013). Deliberative models of participation are also viewed as a means to educate participants about the issue in question as it is being discussed (Abelson et al., 2013; Bolsewicz Alderman et al., 2013).

It is believed that well-designed and executed public deliberation that allows effective interaction among participants and results in social learning and the development of shared meanings and values, has the potential to enhance the legitimacy and acceptability of policy decisions. In turn, this can ensure that health policy and service recommendations are more appropriate, feasible, inclusive, and just. Public deliberation may also increase public buy-in and trust in governing institutions (Solomon & Abelson, 2012)

There are several deliberation models and methods that range, for example, in terms of structure, number of participants, duration of engagement, number of sessions, and extent of educational materials used. These methods include public hearings, citizen juries, community meetings, deliberative workshops, roundtable workshops and deliberative forums among others (Abelson et al., 2013). In some countries where there are formal priority setting institutions in place, like the National Institute for Health and Care Excellence (NICE) in the UK and the Health Intervention and Technology Assessment Programme (HITAP) in Thailand, patient and citizen groups have been established who are supposed to play a role in the decision-making process. In Thailand, representatives of the public are involved in different stages of health technology assessment and the health benefit package development (Slutsky et al., 2016). NICE makes use of a citizens' council comprised of selected representatives of the public, which through deliberation aims to contribute to decision-making by providing the public's views on non-technical considerations for benefit inclusion by the National Health Service. This type of engagement, known as "minipublics", has been used in other settings including Canada, Israel and Australia (Abelson et al., 2007, 2013).

Both aggregative and deliberative methods are intended to overcome the challenge of competing perspectives (plurality) in determining public preferences but also have their limitations. Aggregation fails to consider the reasons and justifications behind the preferences and makes no provision for shifting of priorities after considering others' views. Deliberation, while resulting in priorities that are based on informed and reasoned exchange and debate between individuals, may not always succeed at ensuring true representation and may overlook some important preferences especially if vulnerable groups are not adequately represented (Abelson et al., 2013; Baker et al., 2021). Deliberation also at times fails to consider dissenting views which may exist even after agreement is reached, and may be overshadowed by stronger voices, or undermined by social pressure and confirmation biases (Oortwijn & Klein, 2019). Some have called for an approach that combines both these elements and aims to reach a broader public by considering individual level preferences as well as group decisions (Baker et al., 2021).

1.4.1 The Choosing All Together (CHAT) tool

Another example of a deliberative engagement method is the CHAT (Choosing All Together) tool. CHAT is a simulated priority setting exercise where participants work individually and in groups to distribute a limited number of stickers on a board as they select from a wide range of health care options. CHAT simulates priority setting processes whereby limited resources are available for a wide variety of interventions (Goold et al., 2005). CHAT was originally developed in 2000 by the University of Michigan and the National Institute of Health to include the public in creating health insurance packages and has since been used and modified to explore coverage trade-offs within a variety of audiences including low-income rural residents in India in developing a micro-insurance package (Dror,2007). The tool has been translated into Spanish as well as French, German and Italian for use in Switzerland and has been developed into a computer and web-based version (DECIDERS, 2018). More detail about the tool is provided in Chapter 4 of the Results. One of the original CHAT boards is shown in appendix K. The CHAT board itself is always divided into segments that look similar to a pie chart and the cost of the options on the board are represented by white sticker holes. Beyond this, there is much variation in different CHAT boards and modifying the tool for a specific context requires various steps that include topic identification, specific intervention identification, categorisation and description, costing of the interventions as well as supporting material development. CHAT was designed to overcome some of the barriers of public participation through facilitating a deliberative and interactive process that encourages group decision-making and uncovers the values that drive preferences where resources are constrained (Danis et al., 2010; Goold et al., 2005). Although CHAT is designed predominantly as a group decision-making tool, the exercise also allows for consideration of individual preferences as participants engage with the tool through various rounds including the individual rounds.

1.5 Study context

1.5.1 The South African health system and priority setting

South Africa faces a quadruple burden of disease from HIV/AIDS and TB; non-communicable diseases (NCDs); maternal, neonatal and child mortality; and violence and injury, alongside prevailing health inequities (Mayosi et al., 2012; Pillay-van Wyk et al., 2016). The health system, which aims to address these overlapping disease burdens and address inequities, is currently a two tiered one. The public health sector is poorly resourced and overburdened serving 83% of the population (Ngobeni et al., 2020). The private sector serves 17% the population who derive benefit from private healthcare insurance (Competition Commission, 2019).

Within the public health sector, the priority setting process is a hierarchical one, where decisions are made via top-down processes (Katuu, 2018). At the top of the hierarchy is the National Department of Health (NDoH), followed by nine provincial departments then local and district health authorities (Katuu, 2018). The NDoH is responsible for the development of policy creation and resources. Each of the nine provincial governments is responsible for service delivery decisions and the provision of healthcare services via a district-based healthcare model but are reliant on National Government for unconditional transfers or conditional grants to finance these healthcare services (Edoka & Stacey, 2020). The provincial departments represent the interests of each of the nine provinces, and the local and district levels are supposed to ensure adequate operating of health facilities (Giaimo, 2016). The district health system (DHS) and primary health care (PHC) facilities are considered an essential component of a functioning health system in developing countries to promote equal and efficient healthcare (Fusheini & Eyles, 2016). The provincial health departments assign budgets to individual public sector hospitals and primary healthcare clinics, often based on historical budgeting patterns. Facilities receive funding through line-item budgets, and staff members are compensated through salaries. This has been criticised as a relatively passive process of purchasing services and preventing a more dynamic and active process of purchasing resources and services that better meets population needs (McIntyre et al., 2014; Pauw, 2022). Public sector health facilities offer a fairly extensive array of services, yet implicit rationing is necessitated by the scarcity of specific services. Additionally, there exists a considerable diversity in both the accessibility and quality of services across different geographical areas. (McIntyre, 2014)

Many argue that priority setting processes in South African should, instead of top-down processes, rather involve bottom-up inputs to ensure that the voice of the public is heard and considered, including experiences of users of services, barriers at community and health system levels and social determinants of health (Harris et al., 2011; van der Merwe et al., 2021).

The country is committed to delivering quality universal healthcare by 2025 through a national health insurance (NHI) scheme. The purpose of the NHI is to pool public revenue to create a NHI Fund based on social solidarity that will eliminate the division in health funding between the private and public sectors (National Department of Health, 2019). The NHI Bill is also explicit about prioritising groups in greatest need and who experience greatest difficulty in obtaining care to address inequities and will rely largely on strengthening primary health care through the district health system (National Department of Health, 2019).

A large component of these groups in greatest need reside in rural areas. The rural population of South Africa comprises 52% of the total population and includes 75% of those living in poverty (Vergunst et al., 2016). Those in lowest socio-economic groups are more vulnerable to disease and illness and experience greater lack of access to health care, thereby leading to greater social exclusion (Mangundu et al., 2020; Vergunst et al., 2016). While social exclusion is often due to resource constraints and broader social determinants it also applies when people cannot exercise their voice, leading to a lack of agency in decisions (United Nations Department of Economic and Social Affairs, 2016). Marginalised groups, including rural populations often bare a greater brunt of this. In South Africa, the overall disease burden is higher in lower socio-economic groups largely due to entrenched structural inequalities and is exacerbated by poor access to PHC services and greater social exclusion (van der Merwe et al., 2021). While there is intention to prioritise the most vulnerable there is often a disconnect between what decision makers believe is most important to these groups and what their lived reality is, especially among the most vulnerable, whose voice is often neglected in the design of policies and services (Wariri et al., 2017). Any type of health system reform in South Africa will only succeed by addressing these inequities and fostering social inclusion through the design and implementation of health policies and services that prioritise the most vulnerable, including rural populations.

1.5.2 Public Engagement in priority setting in South Africa

Since 1994, South Africa is governed by its progressive Constitution which upholds participatory democratic principles and considers public engagement in the legislative process a constitutional requirement (Government of the Republic of South Africa, 1996). Various policy documents further entrench these principles. The National Policy Framework on Public Participation states that communities should influence decision-making, and The Parliamentary Public Participation Model asserts that “the intention of public participation and involvement in democratic processes is primarily to influence decision-making processes that reflects the will of the people" (NCOP', 2019; South African Legislative Sector, 2013). With regard to health, public engagement in priority setting is formalised in the National Health Act 61 of 2003 (Amendment Act 12 of 2013), which makes provision for the establishment of community health committees (National Department of Health, 2003). The intention is that these committees ensure public participation in the priority setting process for local clinics, but this does not happen. In addition, there is no specified approach, mechanism, or tool to enable effective participation. While some Community Health Committees do exist with public representation, the role of these bodies is poorly defined, they do not function optimally, and members have little input in decision-making (Haricharan, 2010). Various policy documents have since been developed that further embed the concept of public engagement, yet they do not specify methods or even criteria to accomplish this. Some public engagement efforts have taken place but their role in decision-making is limited (Haricharan, 2010; Padarath & Friedman, 2008; van der Merwe et al., 2021). At the national level, beyond public commenting and consultations, no formal structure for more meaningful public engagement in priority setting exists.

1.6 Justification for the research

The political climate in South Africa is, in theory, supportive of public engagement in priority setting at various levels. However, there are limited context specific tools and applications that enable meaningful engagement through a deliberative approach and where communities can consider resource implications while balancing individual and societal values in reaching consensus regarding trade-offs (Padarath & Friedman, 2008). There is also a large rural population who experience high degrees of social exclusion and a quadruple burden of disease that has an asymmetrical effect on the most vulnerable (Vergunst et al., 2016) . At both the national and provincial/local levels any public engagement that does occur, is typically a passive event, is not deliberative in nature and does not allow for the interrogation of what trade-offs the public might be willing to make within a constrained budget. In addition, where engagement does occur marginalised voices (including rural populations) are often neglected, and the impact on decision making is limited (Haricharan, 2010; van der Merwe et al., 2021). Houston contends that public engagement in South Africa must be improved to abide by the Constitution and to ensure that appropriate implementation of policies is achieved (Houston G et al., 2001).

The aim of my research, therefore, was to modify and implement a deliberative engagement tool- CHAT (Choosing All Together) for a rural South African context to prioritise a package of interventions for a health services package. This is the first time a deliberative engagement tool has been implemented in South Africa which considers health priorities and trade-offs in the context of limited resources. CHAT was chosen as the tool because it is an example of a practical participatory, deliberative approach to address the moral issue of rationing health care and was designed to promote participatory decision-making that is inclusive, deliberative, and accessible to a diverse lay audience (Goold et al., 2005).

1.7 Research aim and objectives

The overall aim of the research was to investigate the feasibility and practicality of meaningfully including the public in resource allocation and priority setting for health in a rural setting in South Africa using a deliberative approach. Specific objectives for the research were to:

- Identify and cost priority health topics and interventions using participatory methods in order to modify the CHAT tool for a South African rural community context (paper 1)
- Explore the group deliberation process and outcomes using CHAT to identify what issues were prioritised by community members, the reasons for these

    - selections and how negotiations and engagements with trade-offs took place within the groups (paper 2)
    - Compare the outcome of the group deliberative process to the individual process for priority setting for health and characteristics that influence decisions at the individual level (paper 3)
    - Discuss the deliberative engagement exercise in terms of its feasibility and potential value for practical and meaningful public engagement in priority setting for health in South Africa

Through this analysis the research sought to develop an understanding of the process of a particular public engagement approach in a rural community as well as the outcome of using this approach. In terms of the process, the analysis was focused on how the negotiations took place within the groups and what types of deliberations and engagement with trade-offs the participants faced when resources were constrained. In terms of the outcomes, the research was interested in determining what priorities were most important to the rural community within a constrained budget as well as the values and characteristics driving these priorities, but also how priorities might differ amongst individuals even within the same rural community, and the importance of transparency in this regard. This work aimed to demonstrate one example of the modification and implementation of a public engagement tool with a vulnerable population and to show how they grappled with limited resources and difficult allocative decisions. In doing so the work could provide insight into how marginalised voices, as well as broader publics, may be meaningfully incorporated in the priority setting agenda.

Chapter 2

2 Literature review

2.1 The global evolution of public engagement in priority setting for health

The late 20th Century saw increased commitments globally to public participation in healthcare decision-making as part of a wider move towards participatory governance (Barnes, 2004). The World Health Organization's (WHO) Alma Atta Declaration on Primary Health Care (PHC) in 1978 was a significant milestone in the Public Health field and affirmed that "people have a right and duty to participate individually and collectively in the planning and implementation of their health care" (World Health Organisation, 1978). Leading up to and following the Declaration, efforts to promote community participation increased and were supported by broader political and social environments where empowerment and liberation were valued. The socioeconomic context of the early 1980s led to watering down of its reach due to health sector reforms emphasizing cost recovery and privatisation (Vos et al., 2009). However, the agenda was further promoted in 1986 through the Ottawa Charter for Health Promotion which focused on governments working with people and enabling health (World Health Organisation, 1986), and in 1989 when WHO published the first substantive study on "community involvement in health development" (Oakley & World Health Organisation, 1989). During the 1990s, participation became a dominant concept in the international health sector. A shift to participatory governance was influenced by the disillusionment with the "democratic deficit", social movements demanding greater accountability and inclusion in decision-making and governments seeking ways to bring them closer to the people (de Freitas, 2017; Vos et al., 2009). This extended to the health care sector and was further ratified by the Health In All policy in 1999 which stipulated that community participation in decision making for healthcare should be ensured at all levels (World Health Organisation, 1999).

From the late 1990s, as health disparities were widening, public health specialist and social activists promoted an agenda addressing inequities. This led to a growing global campaign

for health for all as a fundamental human right, which saw public participation embedded within it (de Freitas, 2017). In 2000 A People's Charter for Health was adopted by members of the People's Health Movement and reiterated the principles of universal comprehensive PHC envisioned in the 1978 Alma-Ata declaration. It emphasised that "now more than ever an equitable, participatory and intersectoral approach to health and health care is needed" (People's Health Movement, 2000). Social determinants of health became essential to the global health agenda and The WHO Commission on Social Determinants of Health (2008) called on governments, policymakers and health activists to particate in the global effort to redress inequities in health as an issue of social justice (Narayana & Narayan, 2012). At the same time, evidence that participation could improve public health interventions began to broaden and led to an increase in investments in public participation in health throughout the 2000s (de Freitas, 2017).
The Astana Declaration in 2018 commemorated the 40th anniversary of the Alma Ata Declaration and reaffirmed commitments to participation in planning and implementing health care (Haricharan et al., 2021; Walraven, 2019). The WHO Framework on Integrated People Centred Health services in 2016 saw public participation as a way of strengthening health governance, and General Comment 14 on the Right to the Highest Attainable Standard of Health (UN 2000) conceptualised participation as central to the Right To Health (Haricharan et al., 2021). According to this agenda, participation meant meaningful participation which includes "decision-making that should occur at local, national and international level" and required member states to put in place mechanisms for participation (United Nations, 2000).

The 2030 Sustainable development agenda, which is premised on leaving no one behind and putting the furthest behind first saw an increased global commitment to UHC to ensure that everyone has access to quality healthcare without financial hardship (United Nations, 2015). This agenda includes promoting social inclusion and prioritising the poorest and most disadvantaged groups in society to address inequities (United Nations, 2016).

In order to achieve UHC, in a global context of competing healthcare demands and limited available resources, there has been a renewed attention on institutionalising priority setting and standardising approaches like health technology assessment (HTA). HTA is a systematic process for determining the value of a health intervention to inform decision making in support of an equitable, efficient and high-quality health system (Krubiner, 2022; O'Rourke, 202). The process is largely based on assessing value for money in healthcare and which interventions and services should be prioritised, directly related to priority setting and often driven by economic evaluations through the application of cost effectiveness analyses (Chalkidou et al., 2016; Weale et al., 2016). HTA has more recently been promoted as an evidence-informed deliberative process which extends beyond costs and benefits and include evidence on social values (Baltussen et al., 2016; Chalkidou et al., 2016; Gauvin et al., 2010).

Public engagement is viewed as one of the mechanisms to facilitate inclusion of social values and there have been some efforts to formalise public engagement within priority setting institutions. As mentioned in the Introduction an example of this is the Citizens Council which is part of the National Institute for Health and Care Excellence (NICE) in the UK and the Health Intervention and Technology Assessment Programme (HITAP) participatory appraisal process in Thailand (Slutsky et al., 2016). While these "minipublics" do include some level of public engagement in the HTA process, the degree of involvement and their impact on the final decisions is questionable, and they may not succeed at representing the broader public, especially marginalised voices (Abelson et al., 2007; Oortwijn & Klein, 2019,).

There are many other examples of public engagement in priority setting in high income settings, most of which are considered in a review by Abelson (2003) and more recently by Arthur (2023) who provides a systematic review of public engagement in decision making specifically for UHC, HTA and pharmaceutical coverage. Both reviews indicate a lack of concrete evidence for the impact of public engagement on decision making outcomes.

Arthur identifies various mechanisms for public engagement in decision making processes related to health service coverage. These mechanisms primarily focus on consultation and involvement, which involve gathering public opinions, experiences, and preferences. Collaborative and empowered engagement (meaningful engagement), where the public actively partners in decision making or has final decision-making authority, were not found in the studies reviewed (Arthur, 2023)

The review notes that most studies included were conducted in high-income countries, suggesting a higher rate of engagement and more formalised decision-making processes in those contexts. Common challenges for engagement included barriers related to structure, norms, institutions, procedures, and technical aspects. Power differentials among stakeholder groups emerged as a significant issue (Arthur, 2023)

The authors found that inconsistencies in conceptualising public engagement and defining meaningful participation hinder clear guidance and identification of best practices. Furthermore, reporting on the involvement of marginalised communities was lacking in the studies reviewed, exacerbating social inequities. The authors conclude that there is a need for greater attention to diversity, representation, and transparent criteria in public engagement initiatives (Arthur, 2023).

In low and middle-income countries (LMICs) moving towards UHC there have been efforts to engage the public in priority setting for health more broadly and in some cases specifically in the design of health services packages.

Uganda operates a decentralised health system and has a constitutional requirement for active public participation in governmental decision making. Subnational levels have established participatory structures, including health committees responsible for planning, budgeting, monitoring, evaluation, and fostering community involvement in decision-making. Additionally, village health teams encourage community engagement in managing local health services.

However, there is a lack of clear guidance on explicit standards for effective participation and the practical implementation of such engagement. Consequently, many groups (are excluded from the decision-making process. Barriers to inclusion encompass financial constraints (limited transportation and lack of incentives), biomedical factors (illness, disability), knowledge-based challenges (low literacy, limited English language skills, and insufficient information on rights and participation opportunities), motivational hindrances (competing needs/commitments, perceived disinterest), socio-cultural issues (women's lack of decision-making power), and structural barriers (hunger and poverty) (Razavi, 2020). Participation by vulnerable populations, especially rural women, is particularly lacking (Razavi, 2020; Kapiriri), due to additional challenges and difficulties in implementing systematic public participation.

This is consistent with other studies demonstrating that poverty is closely linked to inequality problems in relation to meaningful participation. This includes challenges in terms of time and energy that must be allocated to meeting basic needs. Additionally, limited financial resources can hinder the ability to attend public deliberations in distant locations. Lower levels of education not only impact capacity to participate but also affect self-confidence in voicing opinions, particularly among minority groups such as women, ethnic minorities, and others. (Denhardt, 2009; Abers, 2000)

In other settings like Kenya, Tanzania and Zambia a decentralised health care system exists to different degrees and public engagement in decision making is promoted, especially at the district level.

Kenya has particularly strong guidelines for decision making (including planning, budgeting and monitoring) to occur at the individual facility level within the districts and with active involvement from the community through community health committees (O'Meara, 2011) The aim is to ensure that activities align with local priorities and implementation capacity. However, there are challenges in implementing the guidelines.

A study conducted in 2008 demonstrated that there were mechanisms in place to engage the public in developing district level health facility annual plans to ensure these reflected local priorities. The final plans did reflect priorities that overlapped between facility staff, committee members, and national indicators, however, many additional local issues that were identified did not feature. The impact on budget allocation at the district and facility level was also limited. The authors note that the health facility plans that more closely reflected community priorities were the ones that did convene community committees.

Similar observations have been made in Tanzania and Zambia where annual plans were influenced by national and donor priorities rather than decentralised decision-making despite planning guidelines and the presence of similar health committees at the facility and village level. This highlights the issue of power not being effectively transferred to lower levels, as well as complexities in responsibility and accountability (O'Meara 2011; Kamuzora, 2013, Zulu, 2014)

These issues align with findings of other studies on priority setting decisions in developing countries, indicating that priority setting is driven by central government guidelines and influenced by power as opposed to social values (Zulu, 2014).

With regard to health services package design specifically, the evidence demonstrates that there has been some community engagement in LMICs demonstrated mostly by discussions with community stakeholders. However, more structured meaningful engagement with communities to contribute their perceptions of service priorities has been limited (Todd, 2016).

In Ethiopia the Essential Health Services Package was revised in 2018/19 and included public representatives in a process of consultative workshops (develop list of health interventions, agree on prioritisation criteria, gather evidence and compare health interventions). However, lack of direct citizen participation was identified as a limitation and recommendations have been made for the inclusion of town hall meetings to in the next round of revisions in order to elicit public input directly (Todd, 2016).

On the contrary, In Kenya a unique approach involved the use of a community manual on essential health services, enabling communities to prioritise services to be included in the health services package. This was accompanied by a process of capacity building. In Zimbabwe, community-based surveys identified community priorities during the 2013 update of the essential health services package. In both cases, community input was combined with national burden of disease assessments (Todd, 2016).

However, assessing the implementation of the health services package and its translation into local services has been limited in most settings. So too has demonstrating the outcome of the health services packages on fair process and social accountability of services, which is linked to how meaningfully the public has been engaged in its design. In some countries, there is minimal public information as to what services communities can anticipate at different levels and scarce evidence of reporting to the general public to promote social accountability (Todd, 2016). This undermines meaningful public engagement in priority setting for health.

2.2 South Africa’s path to public engagement in priority setting for health

The concept of public engagement in priority setting in SA has evolved since the first democratic elections in 1994 and with the Constitution in 1996 the nature of it radically changed. The right to participate in public affairs, which was denied during apartheid, is protected as a fundamental freedom under the Bill of Rights (Government of the Republic of South Africa, 1996). The Constitution provides that the public must be encouraged to participate in policymaking as one of the basic values and principles governing public administration (South African Human Rights Commission, 2015). The Constitution also places a duty on the Houses of Parliament (National Assembly and the National Council of Provinces- NCOP) and provincial legislatures to facilitate public participation when executing their legislative processes (Bill of Rights, Chapter 2 of the Constitution of the Republic of South Africa Act 108 of 1996). The restructuring of the health care system at the same time from a centralised, predominantly curative one to a decentralised district health system prioritising primary healthcare (PHC) further entrenched the notion of public engagement (RDP, 1994). The intention of public engagement in post-apartheid democratic South Africa focuses on meaningful participation where there is an influence on the decision-making processes to reflect ‘the will of the people’ (Department of provincial and local government, 2007; NCOP’, 2019; South African Legislative Sector, 2013). The White Paper on Transforming Public Service Delivery in 1997, commonly known as the Batho Pele (‘People First') policy, was developed to enhance meaningful public participation in local government decisions to ensure that public service delivery meets the needs of citizens (Department of Public Service and Administration, 1997). The White Paper on local government in 1998 made it explicit that municipalities must require active participation by citizens at different levels to express their views “before, during and after the policy development process in order to ensure the policies reflect community preferences”(Government of the Republic of South Africa, 1998) The Local Municipal Systems Act in 2000 sets out requirements for public participation (Government of the Republic of South Africa, 2000). This extended to healthcare where participation was conceptualised in the White Paper on Transformation of the Health System to include community participation in national policy as well as in different “aspects of the planning and provision of health services” (National Department of Health, 1997). The National Health Act of 2003 formalised public participation in health decision-making and made provision for the establishment of community health committees (CHCs), hospital boards and local health councils (National Department of Health, 2003) . The CHCs are supposed to comprise of one or more local government councillor, head(s) of the health facility/facilities and one or more local community member (National Department of Health, 2003). The Act stipulates that provincial departments of health must develop legislation which identifies the specific functions of the health committee, but the intention is that the CHCs ensure community participation in the governance of and priority setting process for local clinics. Most of South Africa’s provinces have some guideline for CHCs in place but there is no standardisation of roles and responsibilities (Haricharan, 2010). Reviews of CHCs shows that many are not in existence and the ones that are, have very limited roles in decision-making but operate more like pseudo community health workers (Haricharan et al., 2021; van der Merwe et al., 2021). Cited limitations of health committees include lack of clarity on roles and functions, lack of resources, inadequate linkage to communities, top-down decision-making, limited capacity, and poor support among others (Haricharan et al., 2021; Padarath & Friedman, 2008).

The National Development Plan 2030 (from 2013) which focused on health, economic and environmental goals for SA, and the endorsement of General Comment 14 in 2015, further entrenched health care as a human right. As a WHO member state, South Africa is responsible for putting mechanisms in place to facilitate participation which enables decision-making at all levels of government (National Planning Commission, 2013).

South Africa's commitment to achieving quality Universal Health Coverage by 2025 through a national health insurance scheme includes re-engineering PHC services and strengthening the district health system, which in turn will rely on effective public engagement (Haricharan et al., 2021; National Department of Health, 2019). The country is also signatory to the World Health Assembly Resolution (67.23) of 2014 which recognises the importance of health technology assessment (HTA) in the priority setting process for UHC, and the NHI Bill identifies HTA and cost effectiveness standards as key components for determining and refining the interventions that will be covered by NHI (Hofman et al., 2015; National Department of Health, 2019). It is recognised that HTA should extend beyond cost effectiveness analyses to incorporate broader evidence on social values through deliberative approaches (Chalkidou et al., 2016). Public engagement is therefore a potential mechanism to facilitate this. Wide and transparent public engagement on issues of decision-making and prioritisation could be key to the success of SA's path to UHC and tools to engage the public might assist in achieving this.

2.3 Theoretical foundations of public participation and engagement

Any conceptualisation of public engagement in decision-making for health must consider the various ladders and frameworks of participation, originally conceived by Arnstein in 1969 and subsequently developed by other theorists and researchers (Arnstein, 1969; Barnes M, 1999; Burns et al., 2007; Charles & DeMaio, 1993; Cohen J, n.d.; Forbat et al., 2009; Guaraldo Choguill, 1996; Safaei, 2015; Tritter & McCallum, 2006; Wilcox D, 1994). These frameworks of participation interlink with broader engagement theories whose origins are steeped in disciplines of political science, sociology, economics, and development. Arnstein characterised engagement in terms of an eight-rung ladder from manipulation to citizen control and was based on redistribution of power between the officials and citizens, specifically those worst off (Arnstein, 1969). The bottom rungs of Arnstein's ladder (manipulation and therapy) refer to levels classified as non-participation where citizens have no power but are manipulated into believing that they do. This includes strategically allocating members of the public onto committees but with the intention of engineering their support. The middle rungs (informing, consultation, placation) are classified as degrees of tokenism where there is a genuine move to some form of participation but not empowering enough to have significant impact. This includes one-way consultations with the public where information is shared top down or where members of the public are included on advisory boards but where they have little voice and no influence(Arnstein, 1969). The top 3 rungs (partnership, delegated power, citizen control) demonstrate higher levels of citizen agency where meaningful participation takes place. This includes two-way communication mechanisms to allow for the public to express their views as well as to negotiate change, hold officials accountable and ultimately take charge of specific programmes and funding allocations at community level (Arnstein, 1969).

Different variations of the ladder have since followed. Wilcox's ladder, steeped in collaborative theory, has five rungs that demonstrate degrees of involvement: information, consultation, deciding together, acting together, supported independence (Wilcox D, 1994). Burns' ladder of citizen empowerment builds on Arnstein's ladder by providing further detail on the levels of participation and attempts to capture quality of engagement (Burns et al., 2007). Choguill's version of the ladder was developed specifically for "underdeveloped countries" and includes 8 rungs which ultimately aim to influence decisions in the political space. The rungs include empowerment, partnership, conciliation, dissimulation, diplomacy, informing, conspiracy, and self-management. This model is concerned with the potential for organisations to exert harmful influences under the guise of participation (Guaraldo Choguill, 1996).

Specifically in relation to health care, Finegold (1997) conceives a less hierarchical and simpler framework with five degrees of participation from informing, consultation, partnership, and delegated power to citizen control (Safaei, 2015). Eyben's participation model originates from a rights-based development theory and incorporates the recognition of the importance of participation in local political processes (Aylett, 2010). In this model the right to participation is paramount, and only through participation other rights (including economic, social, cultural, and political rights) can be prioritised and resources allocated to support them (Aylett, 2010). Hanley et al (2004) demonstrate involvement of the public in the NHS in the UK in terms of a hierarchy from "consultation" to "collaboration" to "user-controlled" (Safaei, 2015). Thompson (2007) identifies five degrees of participation specifically in relation to the level of patient power: informed decision-making, shared decision-making, professional-as-agent, paternalism (consultation and information-giving), and exclusion (no participation) (Thompson, 2007).

Charles and DeMaio move beyond proverbial ladder rungs and consider a more extensive participation matrix in which domains, role perspectives, and levels interact. Domains refer to the issues to be decided which include 1) treatment; 2) service delivery for a defined region or a particular health facility; and 3) macro health care policies. The role perspectives relate to users of health services and public policy perspectives, the former focused on concentrated interests and the latter with broader public or community interests and levels capture the degree of power or agency conferred to lay people including "consultation", "partnership", and "lay control" (Charles & DeMaio, 1993). Forbat et al identify four models of involvement by identifying different roles of the public (consumer, citizen, partner, and researcher) in four types of activity (purchasing or choosing services, policy and service planning, care practice, and research). Each of the four models is considered to have its own “ideological driver” – Free-market economics, Social-democratic, Experiential knowledge, and Emancipation and empowerment (Forbat et al., 2009).

Tritter and McCallum critique Arnstein’s original model as missing complexity, narrowly focusing on one dimension of power, and unhelpful for developing and sustaining public engagement (Tritter & McCallum, 2006) . They also criticise Arnstein for focusing only on outcomes at the expense of processes of involvement, and for the lack of consideration of methods of engagement, especially regarding framing problems as opposed to designing solutions. They call for considering “multiple ladders” to reflect the diversity of publics and contexts with linkages between them allowing for “horizontal accountability” (Tritter & McCallum, 2006). They propose a non-hierarchical “mosaic” and dynamic model that “captures interactions between individual users, their communities, voluntary organizations and the health care system” at different levels including local, national and organisational (Tritter & McCallum, 2006, p165). This, they believe, would create opportunity for collaboration and shared decision making and facilitate a system of engagement as opposed to an adversarial approach where there is a focus on competition for power (Tritter & McCallum, 2006)

Marent et al also consider multiple dimensions and, drawing on system theory, conceptualize a framework where participation is considered along three dimensions of social, factual, and temporal (Safaei, 2015). The social relates to the distribution of power, similar to other frameworks, however the factual recognizes the mutual exchange of knowledge and experience that expands the range of health care topics, and the temporal dimension aims to capture the dynamic process of participation and the various phases it incorporates. This model also considers the broader environment that impacts healthcare organisations (Safaei, 2015).

Engagement frameworks have undoubtedly been influenced by participatory democracy theorists and some have gone further to follow deliberative democracy theory. Participatory democracy was originally conceived by Aristotle and subsequently developed by Rousseau in the 18th century and later endorsed by John Stuart Mill who argued that a just society was dependent on political participation (Bohman J, 1998; Duncan, 2007). These ideals began to have a stronger influence in the 1960s and were focused on the value of more inclusive democratic institutions whereby citizens can participate collectively in decisions that affect their lives. In 1980 Bessette, in his critique of democratic institutions to reflect the interests of the public, coined the term “Deliberative Democracy”, taking participatory democracy further to include genuine deliberation and consensus driven decision-making, as opposed to aggregation of preferences through voting (Safaei, 2015). Rawls and Habermas further developed the theory and soon it became prominent among political and social scientists (Bianchi, 2008). For Rawls, reason through meaningful deliberation is central to overcome self-interests to ensure a society that is fair and that promotes equal rights for all its members, inextricably linked to his theory of distributive justice. Habermas focuses on procedural justice and contends that fair procedures and clear communication can produce legitimate and consensual decisions by citizens, and in doing so produces legitimate outcomes (Bianchi, 2008).

Some political theorists have attempted to influence the practical application of contemporary deliberative democracy theory by defining its characteristics. Fishkin argues that the lay public must participate in the decision-making process and outlines five essential characteristics for legitimate deliberation: 1) availability of relevant and accurate information to all participants; 2) substantive balance of different positions; 3) diversity of participants and positions; 4) meaningful consideration of the arguments by participants; and 5) equal consideration of views regardless of which participants present them (Fishkin, 2009; Safaei, 2015). Cohen identifies conditions which he considers underpin the theory of deliberative democracy and includes commitment to the respect of pluralism and values in respectful deliberations and transparency in decision-making directly related to the deliberative process (Safaei, 2015). Others like Gutmann and Thompson emphasize the binding nature of deliberated decisions to all parties involved but require that such decisions be provisional and open to change (Gutmann & Thompson, 2004).

With regard to deliberation in health care priority setting, Blacksher, drawing on theoretical foundations which align with many presented here, demonstrates the three essential components of public deliberation (Blacksher et al., 2012). These include providing participants with factual and balanced information that provides a shared knowledge base from which to deliberate; ensuring that individuals with diverse perspectives are represented; and creating and facilitating a setting where values and moral claims/opinions on behalf of those engaged can be voiced and challenged by others (Blacksher et al., 2012). Engagement that includes these components is thought to provide richer data on public attitudes and social values and enable the participants to develop ideas and priorities through deliberation with one another (Abelson et al., 2013).

Daniel and Sabin expand upon the notion of democratic deliberation in the context of health care priority setting by introducing the Accountability for Reasonableness Framework (AFR). Grounded in procedural justice theories, the AFR asserts that achieving consensus on value principles guiding priority setting may be challenging. Instead, the focus should be on establishing a process that generates decisions perceived as legitimate and fair by stakeholders. Engaging the public in priority setting, as well as the ability to challenge decisions, is one component of the AFR to ensure a fair and legitimate process (Daniels, 2008)

In terms of the practical applications of approaches that are steeped in principles of deliberative democracy theory there are many gaps. Abelson et al produced a review of public deliberation in health policy and bioethics and demonstrates that although most of the initiatives meet the minimum definition for public deliberation, and include the components laid out by Blacksher, there is a large degree of heterogeneity and ambiguity within which these core features have been operationalized. Abelson et al conclude that this is largely due to the limitations of current definitions of public engagement, the limited attention paid to them, or both (Abelson et al., 2003, 2013). Importantly, although there are some motivations and formal links being made to connect outputs of public deliberation to decision-making, much more work is needed to understand this component and how to evaluate it. The review also did not consider any engagement initiatives in LMICs, presumably due to a lack of tools and applications in these settings at the time of review. Alderman demonstrates that there are additional barriers to meaningfully engaging the public in priority setting for health in LMICs, which align with those identified by Arthur (2023) and evident in some of the LMIC country examples above. These barriers include physical access, poverty, social exclusion, and the low social status of women some settings (Alderman et al., 2013) Alderman further notes that even though the public in many LMICs may have a constitutional right to participate in decision making, the processes to enable this do not function optimally and most priority setting is dominated by those at the top (Alderman et al., 2013). This is consistent with many of the LMIC examples above.

Assessing the practical application of public engagement initiates is challenging due to a lack of established evaluation criteria. There are, however, some guiding criteria that have been proposed by different authors and that relate to the process and outcome of public engagement approaches. In terms of the process some of the criteria considered important are that the process be legitimate, reasonable, transparent, responsive, equitable and fair; that it ensures mutual respect; and provides time and space to challenge the information provided (Abelson et al., 2003; Danis, 2019; Goold et al., 2019; Thurston et al., 2005). Regarding the outcomes, beyond the impact on decision making, other criteria include satisfaction of participants and a more informed public; degree to which consensus was reached; and identification of priorities and values (Abelson et al., 2003; Danis, 2019; Goold et al., 2019; Thurston et al., 2005).

2.4 Gaps in the literature

The literature review has demonstrated that although there has been a global shift towards increasing public participation in decision making, influenced by moves towards more participatory governance, appropriate frameworks, tools and practical application of meaningful engagement are lacking especially in LMICs and among marginalised populations. This hampers our understanding of engagement in terms of the process of engagement approaches as well as the outcome of these approaches. Although there have been some efforts to include public engagement more formally in decision making structures in higher income settings, the outcome of these efforts in actual policymaking is not clear, nor are there established criteria in terms of evaluating these efforts more broadly. While the theoretical foundations of public participation are strong, and there is clear evidence of a shift towards more dynamic approaches, the factors that influence effective public engagement are not well understood and it is not clear how public engagement should operate at different levels of decision making within the healthcare system. In South Africa, as is the case in other LMICS, there are limited tools and applications that enable a deliberative approach to public engagement and where communities can consider resource implications and balance individual and societal values in reaching consensus regarding trade-offs, and little understanding of practical applications of these tools. This work aimed to address some of these gaps by developing a context specific deliberative engagement tool and implementing this tool within a vulnerable population to show how they grappled with limited resources and difficult allocative decisions as well as the social values and individual characteristics that drove these decisions. In doing so the work could provide lessons on how marginalised voices, as well as broader publics, may be meaningfully incorporated in the priority setting agenda.

2.5 Conceptual framework

Drawing on the literature and theoretical foundations I consider an adapted conceptual framework that guided the work and could serve as a basis for meaningful public engagement in priority setting for health. The framework is constructed as a dynamic cyclical and collaborative one and emanates from the more dynamic conceptualisations of public engagement by Tritter & McCallum (2006), Charles & DeMaoi (1993), and Marent (2013). The framework rests on the notion of meaningful public engagement in priority setting for health where the public is involved in the decision-making activities for health policies and services through deliberative approaches. Meaningful engagement therefore in this context relies on public deliberation methods that incorporate the components laid out by Blacksher of deliberative engagement- factual and balanced information, diverse perspectives, and setting where moral claims can be voiced and challenged (Blacksher et al., 2012). This thesis, however, builds on Blacksher's components and proposes a 4th component for meaningful engagement in priority setting for health, that should be explicit- the consideration of priorities within a constrained budget. This is supported in the literature by Baker who demonstrates that public engagement can be useful for priority setting only where the public is able to consider social values alongside resource allocation where the budget is constrained (Baker et al., 2021). This is linked to the initial objective of my research which was to modify the CHAT tool for a South African rural context using a participatory approach. The CHAT tool fulfilled the requirements of a deliberative method that potentially incorporates Blacksher's components but also includes the element of a constrained budget.

The framework includes different factors that all interrelate and impact one another. These factors include the different levels of decision making; the different perspectives that interact during decision making; the methods that enable public engagement (and the evaluation that further impacts these methods); as well as the broader environment (political, economic, and social space).

The levels of decision making where public engagement can take place are based on De Maio's conceptualisation and includes the macro level policy decisions and allocation of resources usually at national level and the meso provincial/local level which is concerned with service delivery decisions (including what services are delivered, where and by whom) (De Maio,1993). De Maio identifies a third domain which is the treatment level for individual patients but is beyond the scope of this work. This guided the research in terms of the types of interventions that would be included in the modified CHAT board- including macro level policies as well as provincial and local level services. While the work does include clinical and treatment options, these are considered in the context of what should be available to the community, and not in terms of individual treatment decisions. These levels also interact with one another and with the different perspectives in this framework.

The perspectives that my conceptual framework includes are based on two of those in DeMaio's framework- user and public policy perspective (DeMaio, 1993). The former is focused on concentrated health interests of oneself, family or close community while the latter is concerned with the broader public or community (societal interests). The modified conceptual framework includes a third perspective- that of the decision maker. All perspectives interact and influence one another. By including the decision maker perspective and the impact that all perspectives have on one another there is an attempt to move from what Tritter and McCallum describe as an adversarial approach characterised by power struggles embedded in hierarchical engagement frameworks like Arnstein's ladder, to a collaborative shared decision making one (Tritter and McCallum, 2006). Within my research I consider the perspectives of both individuals and groups from the rural community but also the perspective of national and provincial/local decision makers in the modification stage. My discussion aims to identify some ideas of how to move towards more collaborative decision making.

The methods of public engagement, incorporating the components laid out by Blacksher (2012) as well as the additional proposed constrained budget component, may change over time depending on the situation and the way in which different factors and perspectives interact, as well as the evaluation of these methods. The design of these methods should also include the public as per Tritter and McCallum's framework (2006). This is directly connected to the approach that was taken for modifying the CHAT tool using a participatory approach. Furthermore, I discuss considerations for the use of different methods at different times and the need to strengthen evaluation of these methods.

Finally, the broader social, political, and economic environment influences the perspectives and the levels of decision making (Marent, 2013), and is included in my framework. This framework represents a dynamic evolving system of public engagement for priority setting.

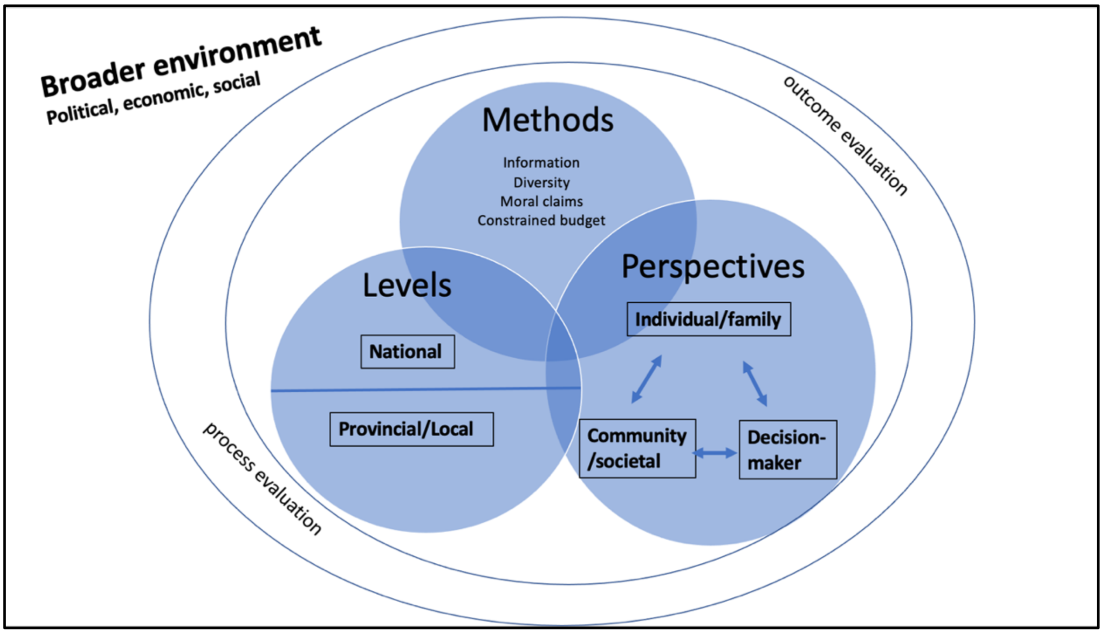

Figure 1. Conceptual framework for meaningful public engagement in priority setting for health, adapted (Tritter & McCallum, 2006; Charles & DeMaoi, 1993; Marent, 2013)

Chapter 3

3 Research methodology

To address the objectives of my study I used a mixed methods approach that included qualitative and quantitative aspects, and resulted in three peer review journal articles, two of which have been published and one submitted. This chapter presents the overall methods and how they are related to each objective as well as to the theoretical approach guiding the methods. It also demonstrates my positionality as a researcher and describes my level of involvement in the method design, data collection and analysis.

3.1 Research philosophy

The overall guiding philosophy was based on an interpretivist/constructivist paradigm. This approach seeks to understand the human experience and suggests that reality is socially constructed. Researchers who follow this approach rely on the perspectives of participants, acknowledging the influence of their own background and experiences, and develop a theory or pattern of meanings throughout the research process. The methods that support this approach are often qualitative or mixed methods, but quantitative data is sometimes used to expand upon the qualitative data (Mackenzie & Knipe, 2006). My work relied predominantly on qualitative data analysis but did include some quantitative data analysis. The perspectives of participants, as individuals and as a group, were central to the work and meaning was developed through the analysis of these perspectives.

3.2 Research setting

The CHAT tool was modified for and implemented in the Agincourt Health and Socio-Demographic Surveillance System (HDSS) study site (https://www.agincourt.co.za/) of the MRC/Wits Rural Public Health and Health Transitions Research Unit. This site in the Agincourt area of the Bushbuckridge sub-district 500 kilometres northeast of Johannesburg, South Africa in Mpumalanga Province adjacent to Mozambique. The MRC/Wits-Agincourt Research Centre has generated socio-demographic data since its inception in 1992 through annual HDSS census updates that capture vital statistics, including births, deaths, and in- and out-migrations. The site covers a land area of 420km^2 and is comprised of 31 villages, 20,000 households and a population of approximately 117,000. The area is typical of rural areas in South Africa characterised by poverty and underdevelopment and where traditional leadership operates a land tenure system (Twine et al., 2016).

The area is characterised by a quadruple burden of disease of HIV/AIDS and tuberculosis (TB); non-communicable diseases (NCDs); maternal, perinatal, and nutritional conditions; and injuries (Kabudula et al., 2017). There are two health centres and six satellite clinics in the study area and three district hospitals within 20-60km away. Sanitation systems are poor and unemployment rates are high. Every village does have a primary school and most have a high school, but the quality of education is poor. Agincourt engages successfully with the local community structures, including traditional village leadership and local service providers, before, during and after research is conducted, ensuring that the community is involved throughout the process. This has been facilitated by a dedicated Public Engagement office that was established in 1994 and that works closely with a Community Advisory Board (CAB), which is an elected body and representative of all villages in the study area (Twine et al., 2016).

3.4 Study design

A sequential exploratory mixed methods study was conducted. The study took place over two distinct phases. The first phase included the modification of the CHAT tool and included a rapid desktop review, three focus group discussions, a modified Delphi process and a costing exercise. This phase also included the design of the CHAT board and materials accompanying the board including a user manual and scenario cards. The second phase was the implementation of the modified CHAT tool with seven community groups in Bushbuckridge and an accompanying socio demographic questionnaire. An overview of each phase is provided below and summarised in table 1. Further detail is provided in the results chapters that follow.

Table 1. Overview of research methods linked to objectives

Study phase	**Specific objective**	**Data collection and tools**	**Data analysis**
1: CHAT modification	Identify and cost priority health topics and interventions in order to modify the CHAT tool for a South African rural community context	1. Rapid desktop review 2. Focus Group Discussions 3. Modified Delphi-voting and follow up ranking 4. Costing and allocation of sticker value	1. thematic content analysis 2. qualitative analysis using thematic coding 3. Borda count 4. costing template developed in excel and existing actuarial model used for sticker allocation
2a: CHAT implementation	Explore the group deliberation process using CHAT to identify what issues were prioritised by community members, the reasons for these selections and how negotiations took place within the groups	1. Socio-demographic questionnaire 2. Group choices from the CHAT exercise	1. descriptive statistics 2. descriptive statistics and qualitative content analysis- deductive and inductive
2b: CHAT implementation	Compare the choices of the group deliberative process to the individual process using CHAT and the characteristics that influence decisions at the individual level	1. Socio-demographic questionnaire 2. Individual sticker allocations and groups sticker allocations	1. descriptive statistics 2. statistical analysis to show median and interquartile range in STATA 3. Wilcoxon rank sum tests in STATA to show differences in sticker allocations

3.5 Phase 1: CHAT modification

Objective: Identify and cost priority health topics and interventions in order to modify the CHAT tool for a South African rural community context

My research was focused on meaningful engagement in decision making and so I attempted to apply principles of participatory engagement from the outset in the design of the study. CHAT had been modified previously for other contexts and some of these modification approaches had included a degree of community or expert consultation, but my intention was to develop an approach for modifying CHAT that considered the voice of those on the ground as well as decision makers at National, Provincial and district levels, and to consolidate these viewpoints. Hence, an iterative participatory process was developed whereby several stages were followed and data were triangulated to modify the CHAT tool for rural Bushbuckridge.

3.5.1 Research preparation

Prior to the study design I consulted with one of the original developers of the CHAT tool- Marion Danis who subsequently joined the project as an advisor. Danis provided insight and terms of the tool itself and the requirements for modification and implementation. She continued to provide valuable expert guidance for the duration of the study.

At the outset, before the work had commenced, I also engaged with the CAB to consider their input into the design of the study and the CHAT tool. I attended a meeting with 10 members of the Community Advisory Board (CAB) in Bushbuckridge. As representatives of all the villages in the study site they provided invaluable input into the conception of the work. They discussed some of the health issues the communities were facing (many related to access barriers) and provided feedback on an original version of the CHAT tool. In general, the CAB was supportive and excited about the prospects of a tool that would assist the community to grapple with resource allocation decisions for health care. Their insight guided the next stages of the work.

3.5.2 Data collection and analysis

Rapid desktop review

First, a rapid desktop review was conducted. A Rapid review is defined as "a form of knowledge synthesis that accelerates the process of conducting a traditional systematic review through streamlining or omitting various methods to produce evidence for stakeholders in a resource-efficient manner" (Hamel et al, 2021). This method was appropriate as it was intended as the initial step of the research project to develop a preliminary understanding of national and provincial/district level priorities with regard to healthcare, and associated interventions. This information needed to be collected timeously to guide the following steps of the research and to draw on at later stages in the work. The review included a total of 15 health policy documents from National, Provincial and District levels. As is the case with most rapid reviews, descriptive synthesis was used to tabulate the results. Through this analysis priority health topics/issues and related interventions at the national level and specifically for Mpumalanga Province and Ehlanzeni district (in which Bushbuckridge is located) were identified (Further detail is provided in chapter 4 of the results section).

Focus group discussions

Second, three focus group discussions (FGD) were conducted. FGDs, which originated from Emory Bogardu's social psychological research in 1926, are commonly used as a qualitative method to gain in depth insights into social issues. This approach involves the assembling of "a group of individuals to discuss a specific topic, aiming to draw from the complex personal experiences, beliefs, perceptions and attitudes of the participants through a moderated interaction". (O.Nyumba et al., 2018). Focus groups do not aim to reach consensus on the discussed issues. Rather, focus groups ‘encourage a range of responses which provide a greater understanding of the attitudes, behaviour, opinions, or perceptions of participants on the research issues’ (Hennink 2007: 6). This included one with 13-home based carers (HBC) from Bushbuckridge, another with seven provincial/district level decision makers and finally one with eight national level policymakers. The three specific HBC organisations were convenience samples based on proximity to facilitate transport to a central location. Only HBCs who could speak English were selected but most HBCs who work in Bushbuckridge do speak some English. For the second FGD (Prov/District FGD) participants were selected using purposive sampling to ensure diversity across directorates within the Department of Health (DOH). For the third FGD (National FGD) participants were selected using purposive sampling to ensure a broad representation from different directorates within the National DOH.

Modified Delphi

Third, a modified Delphi approach was used to reconcile and refine the priority topics for Bushbuckridge. The Delphi technique was originally developed for generating forecasts but is often used in social science research to reach consensus through recording opinions or decisions from independent experts over various rounds often through the use of a question or a ranking scale (strauss & zeigler, 1975). At the end of each of the FGDs participants voted on each health topic/issue. Topics/issues that received majority vote were included in a follow up ranking process using email to the participants from the home base carer FGD and the Provincial/ District experts. This enabled us to refine the topics/issues for Bushbuckridge. There was a total of 13 topics/issues included in the follow up ranking. In order to determine the overall ranking score, we used the Borda count method as described in chapter 4.

The top seven health topics/issues were selected for the final CHAT board. The specific solution/interventions under each of the topic/issues were refined and finalized by referring back to the qualitative data from the FGDs as well as the desktop review to ensure sufficient detail was included.

Costing exercise

Fourth, a costing exercise was undertaken to depict the cost of interventions within the different topics/ issue and to enable the design of the CHAT board depicting the relative costs. The intention was not necessarily to depict entirely accurate costs for all the options on the board but to enable participants to grapple with resource allocation trade-offs and to consider the process and the outcomes of this. The costing methodology is described in Chapter 4, with more detail provided here. Although the aim was not to allocate true costs that would accurately reflect a health services package, we did aim to ensure that the costs of each intervention relative to another was as accurate as possible. Costing included both programme and patient-related costs. Programme costs included those incurred at the community and district levels rather than the health facility level itself (such as training, mass media, workshops in schools and communities). Patient costs consisted of diagnostic and laboratory tests, personnel and labour, drugs and supplies, and hospital and health centre visits. Total costs were obtained by multiplying quantities by prices.

Table 2 shows the sources which were used for price/unit costs of the different components of the interventions. Staff remuneration was based on current salary structures of health workers in South Africa and data were obtained from the Department of Public Service and Administration database. The valuation of examinations and investigations was based on different treatment parameter costs from the Uniform Patient Fee Schedule (UPFS) 2018 of the National Department of Health. Where cost information for the public sector was not available, we relied on the National Health Reference Price List - the latest (2006) legal tariff document at the time for the public sector. Public sector costs were assumed to be 70% of private sector costs. Medication costs were extracted from the South African National Health Laboratory Service State Price List report 2018. For Bushbuckridge-specific parameters we relied on the Ehlanzeni District Health Plan (DHP) 2017/18 and the Bushbuckridge Local Municipality (2011) Integrated Development plan: IDP 2011-2016. Cost components and unit costs were developed based on researching existing programmes that offered similar interventions. Previous research done by PRICELESS SA (http://pricelesssa.ac.za) was also key to identify the components and cost of interventions on stillbirths, diarrhoea and maternal, newborn and child mortality (Chola et al., 2015; Michalow et al., 2015) For information on costs of education and information provision we relied on expert consultations with stakeholders from both the MomConnect mobile messaging initiative at the National Department of Health and from the Healthy Living Alliance (HEALA) a non-governmental organisation which has extensive experience in public awareness campaigns. We searched the literature published from the MRC/Wits-Agincourt Unit and conducted expert consultations for relevant publications.

Table 2 Data categories and sources for CHAT costing

Data category	**Parameter**	**Source**
Population estimates	Population of all age groups Estimated pregnant women	Integrated Development Plan: IDP 2011-2016
Epidemiology parameters	Disease burden Medicine and technology need and usage Hospitalization Outpatient visits	Ehlanzeni District Health Plan (DHP) 2017/18 Literature review
Infrastructural and managerial parameters	Service delivery platforms for health Human resources for health for health	Ehlanzeni District Health Plan (DHP) 2017/18
Direct medical costs	Medication	South African National Health Laboratory Service
	Examinations and investigations	Uniform Patient Fee Schedule 2018 The Lives Saved Tool
	Health workers wages	Department of Public Service and Administration
Education provision	Mobile phone messaging Media campaigns	Stakeholder consultations

Ad hoc searches were also undertaken in the Google and Google Scholar search engines for relevant literature on population health in Bushbuckridge. The literature was collated and assessed for relevant information that could be used to populate the costing template.

Actuarial costs were estimated by factoring in likely utilization rates. An Excel sheet was developed in Microsoft Excel to aggregate cost components. Interventions were expressed as a percentage of total costs and were converted to a relative number of stickers. Our starting point was 0.5% =1 sticker using an existing actuarial model developed by Milliman (www.milliman.com), an international actuarial company that has experience in the adaptation of CHAT, but some allocations were revised based on the judgement of the authors, and expert consultation. The stickers represented the monetary resources that would be required when specific interventions were selected.

3.5.3 CHAT board and supporting materials

Finally, the actual CHAT SA board was developed based on the results from the steps above and was translated into the most widely spoken vernacular language (Xitsonga) in the study area. A user manual was also developed which explained each category of intervention in detail by listing the specific interventions and components as well as context specific scenario cards to demonstrate the consequences of choices made during the CHAT exercise. These cards were developed drawing on the qualitative data that emerged from the FGD with the home-based carers to ensure the scenarios were appropriate for and relevant to the context. The materials were translated into the local language of Xitsonga and were checked by two individuals familiar with this language.

The CHAT SA tool was tested with a group of 11 community members (nine females and two males) from Bushbuckridge. Materials were adjusted slightly and finalised after the test. The final adapted CHAT SA board for rural Bushbuckridge is included in appendix B.

3.6 Phase 2: Chat implementation

Objectives:

- Explore the group deliberation process using CHAT to identify what issues were prioritised by community members, the reasons for these selections and how negotiations took place within the groups
- Compare the choices of the group deliberative process to the individual process using CHAT and the characteristics that influence decisions at the individual level

3.6.1 Participant selection

Sixty-three individuals participated in seven group deliberations using CHAT, with 6-11 individuals in each group over a period of two months in 2018. Purposive sampling was used to include participants from a range of six villages. These villages included three with clinics in the village and three without; three with tarred roads and three with dirt roads to ensure inclusion of villages with different levels of development as well as different barriers to accessing healthcare. The participants were selected to ensure a mix of females and males in each of the groups except for two which included one all male group and another group which included predominantly females. The participants were also selected based on age to ensure a mix of age ranges. Seventy participants were recruited face to face by experienced fieldworkers who explained the purpose of the study and invited them to participate. The final number of participants comprised 63.

3.6.2 Training of fieldworkers

For phase 2 of the study (implementation of CHAT) a facilitator and fieldworkers from Agincourt HDSS were responsible for implementing the tool and transcribing the data. This was because the CHAT groups were conducted in the local language of Xitsonga, and it was therefore more appropriate for the local fieldworkers to conduct the sessions. The facilitator was responsible for guiding the participants through the CHAT exercise using a detailed facilitator script while the fieldworkers were responsible for assisting participants (especially those who were illiterate) with the user manual and transcribing and translating the qualitative data. To successfully conduct research using CHAT, different iterations of training were required. Therefore, a training package for fieldworkers and facilitators was developed by me as PI of the study. This included an introduction to qualitative research methodology; an introduction to the key principles of priority setting in health care; and finally, familiarisation with the CHAT tool itself. I, along with two other researchers conducted the training session in Mpumalanga over a three-day period. All components were delivered through interactive exercises, lengthy group discussions and were key in ensuring that fieldworkers and the facilitator developed the necessary background knowledge for the research and could reach their full potential when conducting the CHAT groups. To enable the fieldworkers and facilitator to engage with the CHAT board and the various supporting materials, part of the training was spent "practicing" the CHAT exercise. They generally found the exercise user-friendly and informative. This was reinforced during the wrap-up session on day three, when field workers were asked to recall what they learnt during the two days. They showed an extensive understanding of both priority-setting and the CHAT exercise.

3.6.3 Data collection

Prior to the CHAT exercise all participants completed a short self-administered demographic questionnaire. CHAT was implemented over three different rounds. During each of the seven FGDs, after the facilitator explained the board, participants individually allocated 35 stickers to the health issues and interventions that they perceived to be the highest priorities for their own family (round 1). Once this was complete the group completed a board collectively in terms of their priorities for the entire community of Bushbuckridge (round 2: group round). The group rounds were led by a trained community facilitator who was guided by a detailed script (appendix C*).* The groups were expected to reach consensus on sticker allocation through majority vote. The entire deliberation process was audio-recorded with consent from participants. Scenario cards were used by the facilitator to assist participants in thinking through the implications of the decisions that they made. During the final round (round 3) participants were again asked to complete the exercise individually thinking about which priorities they believed were most important for their own family.

3.6.4 Statistical analysis

I used descriptive statistics to describe the study participants using the data from the questionnaire and to show the group choices from the stickers allocated on the boards from the groups rounds.

The sticker allocations of all study participants were recorded at each stage of the study. From these the number of stickers allocated to each topic by the participants was calculated by adding up the number of stickers across interventions selected by the participant by topic. The median and interquartile range across study participants was calculated for the topic totals. To examine differences in sticker allocations, Wilcoxon rank sum tests were performed for differences across participant categories and sticker allocations in round three. This test is normally used to compare two groups of nonparametric data (Fay, 2010) and was therefore appropriate for my analysis. More detail is provided in Chapters 4 and 5.

3.6.5 Qualitative analysis

The group rounds of CHAT were recorded, transcribed and translated from the local language, Xitsonga, into English by two fieldworkers. Qualitative analysis was employed using thematic analysis by applying both the codebook approach and the reflexive approach (Braun and Clarke, 2012; Braun et al. 2009). Codebook approaches make use of a structured codebook which is developed prior to data analysis. The themes or categories are identified based on research objectives and the content of the data. The themes represent the key ideas or patterns that are expected to be found in the data and include clear descriptions/ definitions.

A systematic approach is applied to identifying segments in the data that match the predefined codes. As the coding process progresses the codebook can be refined (King and Brooks, 2017; Smith and Firth 2011). Initial codes were developed deductively based on the research objectives and the health topics/ issues on the CHAT board. Sub-codes were developed based on the interventions under each health topic/issue and were classified in the same way as the CHAT user manual- according to promotion (education); prevention; diagnosis (screening); treatment; rehabilitation; palliative care. The codes were defined, and colour coded in MAXQDA and were applied to the data. This enabled capturing of the issues that were prioritised by the groups.

Reflexive thematic analysis is used to explore the patterns, meanings and experiences present in the data. It emphasizes the researcher's active engagement with the data and encourages reflection on their own perspectives and biases throughout the analysis process (Braun et al 2019). After in depth reading of the data initial short codes are developed that capture meaningful aspects of the data and these are further grouped into themes. The process is flexible, and themes can be adjusted or refined as the analysis progresses.

Inductive codes were identified through deep reading of the transcripts by the PI and a second coder and definitions were developed. These codes were mostly linked to the CHAT deliberative process and included deliberations; trade-offs; resource allocation; and shift in prioritisation. Codes were reviewed by a second coder and revisions were made for greater clarity through discussions. The codes were then applied systematically to all transcripts supported by MAXQDA 20.

3.7 Ethical considerations

The PhD was approved by the University of the Witwatersrand Human Research Ethics Committee (HREC Medical), clearance number M161009 (*Appendix A*). Individual participation in the study was voluntary and participants were informed that they could withdraw at any point if they so wished. All participants were provided with a participant information sheet in the local language that explained the study in detail, and this was read by the fieldworkers to participants who were illiterate (*Appendix D; E; F- English versions)*. The facilitator/ researcher also verbally conveyed the research aims and objectives and gave participants a chance to ask questions or clarify information. Once participants agreed to partake in the study, they signed an informed consent form as well as a separate consent to audio recording *(Appendix G; H; I)*. Those that were illiterate were assisted by the fieldworkers in understanding the consent forms. During the CHAT exercise fieldworkers assisted illiterate participants with reading the user manuals. The research ensured confidentiality and anonymity of study participants by using unique study codes instead of participants' names and identifiers. Data was stored in the case study database using these unique codes only. Access to the data was limited to me as PI, the academic supervisors (Nicola Christofides, Karen Hofman, Kathleen Kahn), another senior researcher who provided oversight in statistical analysis (Nicholas Stacey), and the translator and/or transcribers. Audio-files obtained during the study and transcripts are kept in my password protected computer, and hardcopy material and questionnaires stored in a locked cupboard in my office.

3.8 Role of the PhD candidate during the research process and positionality

As the PI of this study, I was committed to ensuring a participatory approach was followed for the various steps. I was aware that as a white, urban woman unable to speak the local language I would be disconnected from some of the data collection and so the design of the methods was carefully considered. The engagement with the community advisory board at the outset, as described above, was also important in the design of the study and the CHAT tool. My background in political science, law and sociology helped conceptualise the work in terms of broader factors and social constructs that influence our realities, as well as the democratic rights underlying public engagement. As such, I was determined to try and show how marginalised voices could be included in important resource allocation decisions that impact people's lives. My experience with communities on the ground (as I had worked with NGOs) and my current experience at the time with policymakers (in the research to policy space) revealed a disconnect that I was hoping to bridge. The lived experience seemed mostly neglected by decision makers where it mattered most, and communities were excluded from resource allocation discussions. In thinking through the design of the research methodology I was hoping to include an approach that was participatory and iterative and that considered voices from above and below but emphasised the local context. This was in some way achieved through the modification process.

I conducted the desktop review as well as the focus group discussions with the national and provincial/district level experts. In terms of the focus group discussions with the home-based carers, I conducted these alongside a site-based manager who spoke the local language. The discussions were conducted in English but at times the carers switched to their local language and the support offered by the site manager was extremely valuable. Although I was an outsider to these home-based carers, they seemed generally comfortable with my presence and were willing to share information. The district and provincial level experts also seemed to appreciate the exercise and were forthcoming with information. Interestingly, the national level policymakers, many of whom I had engaged with previously, were not as forthcoming and the discussion required a considerable amount of prompting.

The costing exercise was conducted by the PI and a researcher (Agnes Erzse) who was involved in the project and whom I had trained in the use of CHAT. We spent many hours discussing the assumptions and consulting with experts because costing data in SA is limited. The final design of the CHAT board, user manual and scenario cards were developed by me with this same researcher. The icons for the board were designed by me and Agnes Erzse in conjunction with medical art designers at the US National Institutes of Health.

Phase 2 of the study (implementation of CHAT) was led by the facilitator with support from the fieldworkers whom we had trained in CHAT, and oversight was provided by the site-based manager as well as Agnes Erzse for some of the groups. After each CHAT session the site manager and I would communicate either by telephone or via email where we would discuss the main outcomes, any challenges, and the plans for the next focus group. Qualitative data analysis was conducted by the PI with regular feedback meetings with one of the supervisors (Nicola Christofides) and a secondary coder reviewed the qualitative coding. For the quantitative statistical analysis, I underwent training from two of the senior researchers (Nicola Christofides and Nicholas Stacey) involved in the study and then performed the analysis with review and input from these researchers.

My position within this study was not a neutral one and therefore reflexivity is important to consider, as is the case most often with qualitative research. Based on my previous experience in the research to policy space and in the NGO space, as well as my background in sociology my viewpoint at the start of this study was that public engagement in priority setting for health is beneficial and should be endorsed. Furthermore, my interest in the CHAT tool specifically, was driven by my belief that the tool was a beneficial one for meaningful public engagement. Throughout all stages of the research, I reminded myself to apply a critical perspective and to consider the shortcomings of public engagement approaches, and of the CHAT tool, and to capture the interpretation of the participants as objectively as possible, cognisant of my own perceptions that might have impacted these interpretations.

Results Chapters

Chapter 4

Tugendhaft A, Danis M, Christofides N, Kahn K, Erzse A, Gold M, Twine R, Khosa A, Hofman K. 2022. CHAT SA: Modification of a Public Engagement Tool for Priority Setting for a South African Rural Context, *International Journal of Health Policy and Management*, 11: 197-209. doi: 10.34172/ijhpm.2020.110

4 Paper i

CHAT SA: Modification of a Public Engagement Tool for Priority Setting for a South African Rural Context

Abstract:

Background: Globally, as countries move towards universal health coverage (UHC), public participation in decision-making is particularly valuable to inform difficult decisions about priority setting and resource allocation. In South Africa, which is moving towards UHC, public participation in decision-making is entrenched in policy documents yet practical applications are lacking. Engagement methods that are deliberative could be useful in ensuring the public participates in the priority setting process that is evidence-based, ethical, legitimate, sustainable and inclusive. Methods modified for the country context may be more relevant and effective. To prepare for such a deliberative process in South Africa, we aimed to modify a specific deliberative engagement tool- the CHAT (Choosing All Together) tool for use in a rural setting.

Methods: Desktop review of published literature and policy documents, as well as three focus groups and modified Delphi method were conducted to identify health topics/issues and related interventions appropriate for a rural setting in South Africa. Our approach involved a high degree of community and policymaker/expert participation. Qualitative data were analysed thematically. Cost information was drawn from various national sources and an existing actuarial model used in previous CHAT exercises was employed to create the board.

Results: Based on the outcomes, seven health topics/issues and related interventions specific for a rural context were identified and costed for inclusion. These include maternal, newborn and reproductive health; child health; woman and child abuse; HIV/AIDS and TB; lifestyle diseases; quality/access; and malaria. There were variations in priorities between the three stakeholder groups, with community-based groups emphasising issues of access. Violence against women and children and malaria were considered important in the rural context.

Conclusions: The CHAT SA board reflects health topics/issues specific for a rural setting in South Africa and demonstrates some of the context-specific coverage decisions that will need to be made. Methodologies that include participatory principles are useful for the modification of engagement tools like CHAT and can be applied in different country contexts in order to ensure these tools are relevant and acceptable. This could in turn impact the success of the implementation, ultimately ensuring more effective priority setting approaches.

Keywords: Priority Setting, Public Engagement, Universal Health Coverage, Rural Health, Health Equity

Key Messages:

1. **Implications for policy makers**
    - Policymakers may benefit from the inclusion of the public in determining the priority setting agenda, not simply from the inclusion of the public once the potential options have been predefined
    - Modification of public engagement tools is resource and time intensive and should take place ahead of time to ensure the tool is available for use during priority setting processes
    - The modified CHAT tool can serve as a basis for further modifications for different settings in South Africa and elsewhere in Africa
    - Participatory methods are feasible in the modification of a public engagement tool like CHAT and can be applied in different country contexts in order to ensure these tools are relevant and acceptable thereby strengthening the priority setting process

2. **Implications for public**

Cost effectiveness analyses are becoming increasingly important in allocation decisions for health coverage, but this process alone does not comprehensively consider public values, and public deliberation is therefore a potential mechanism to fill this gap by incorporating social values into the priority setting process. Public engagement on issues of decision-making and prioritization could be key to the success of setting priorities and context-specific tools to facilitate this process could be useful. Community engagement is important in not only identifying social values for final coverage options for health service packages but also for identifying the initial topics/ issues and specific interventions that should be weighed up when thinking about these packages. By bringing the voices of decision makers and the public together the priority setting agenda can be set not just by experts but also by the public. This could ultimately ensure priority setting approaches that are not only evidence-based, but ethical, legitimate, sustainable and inclusive.

Background

Public engagement in priority setting for health is the practice of actively involving members of the public in the decision-making activities of health policy development, which can also include health service design and planning.(Florin, 2004; Alderman, 2013) The moral values of transparency and public engagement are widely recognized by health systems experts and ethicists.(Childress, 2002; Clark, 2012; Daniels, 2000 ; Sibbald, 2009) These perspectives demonstrate that health priority-setting should reflect the values of the public, and the decision-making process. Beyond improving the ability of the public to influence decisions on issues that affect their lives, public engagement has the potential to reinforce the legitimacy and the public acceptability of the decision-making process and its outcomes; increase the success rate of policy implementation; manage community expectations and improve public understanding of the issues considered. (Scuffham, 2014; Caddy, 2001) Public engagement in decision-making is also viewed as particularly valuable to inform difficult decisions about priority setting and resource allocation as countries move towards universal health coverage (UHC). (World Health Organisation, 2014; Weale, 2016)

In low and middle-income countries (LMICs), public engagement for priority setting for health, particularly at the local level, is promoted. There are some examples such as those in Uganda, Tanzania, Indonesia and India where public engagement structures have been put in place and where there has been some degree of participation and subsequent impact, albeit small scale, on decision making.(Alderman et al., 2013; Kamuzora, 2013) (Kapiriri 2003). The effectiveness of public engagement in decision making in these settings, however, is unclear and in many circumstances, even where the public has a constitutional right to be involved, the processes for engagement do not result in meaningful participation.(Alderman, 2013 ;Kamuzora, 2013) This is due in part to political, practical and cultural factors including barriers to physical access, poverty, social exclusion, disconnect between local and national priorities, time constraints and lack of oversight among others.(Alderman, 2013)

While public engagement is widely endorsed, many questions remain about how best to achieve this. (Abelson, 2003; Abelson, 2013; Alderman, 2013; Slutsky, 2016) Methods of engaging the public in priority setting fall broadly into non-deliberative and deliberative processes. Non-deliberative methods may be consultative in nature, but they do not provide the same degree of consideration, nor of two-way communication and debate that deliberative methods offer. Deliberative methods involve deeper engagement and considerations of choices among a selected group of individuals. (Abelson, 2013). According to the American Institute for Research:

> *"Public deliberation is a unique way of convening a diverse group of citizens to consider an ethical or values-based dilemma and then weigh alternative—often competing—views…[it] rests on the democratic principle that important societal decisions are best made by policymakers in partnership with an informed public"* (AIR, 2015).

Abelson and colleagues outline three components of public deliberation which enhance data richness on public attitudes and values and enable participants to develop ideas and priorities through interaction. These include providing participants with factual and balanced information that provides a shared knowledge base, ensuring that individuals with diverse perspectives are represented, creating a setting where values and moral claims/opinions can be voiced and challenged. (Abelson, 2013)

Deliberative engagement processes have been proposed for priority setting where issues are complex and there are diverse public perspectives. This type of engagement is considered useful in identifying and balancing individual and societal values, and concerns and driving collective outputs (Carman et al., 2015b). There are a number of deliberation methods that range in structure, number of participants, duration of engagement, number of sessions, and extent of educational materials. (Abelson, 2013; Carman, 2013).

One method of public deliberation is through the use of the CHAT (Choosing All Together) tool[*]. CHAT is a game-like exercise where participants work individually and then in groups to distribute a limited number of stickers on a board as they select from a wide range of options. The stickers, which represent the available budget, are only able to cover approximately 60% of the options on the board. CHAT simulates priority setting processes whereby limited resources are available for a wide variety of interventions, and trade-offs are inevitable. (Goold, 2005) CHAT was designed to overcome some of the barriers of public participation through facilitating a deliberative and interactive process that encourages group decision making. (Goold, 2005; Danis, 2010) It was originally developed in 2000 by researchers at the University of Michigan and the U.S National Institutes of Health to include the public in creating health insurance packages and has since been used and modified to explore coverage trade-offs within a variety of audiences, often low-income groups, and in relation to placing priorities on various types of assets. This has included, among others, engaging community members in California to define a basic health coverage package, engaging low income employees in

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[*] CHAT has a licensing fee that is waived where its use/modification is in collaboration with one of the developers

the U.S. to identify employee benefits packages, including low income urban residents in identifying priorities to address the socio-economic determinants of health, involving patients in developing a coverage package for advanced cancer care and for mental health, engaging members of the public in Switzerland to identify a health insurance package and engaging low income rural residents in India in developing a micro-insurance package. (Ginsburg, 2006; Danis, 2014; Danis, 2007; Dror, 2007; Goold, 2018; Danis, 2010; Hurst, 2018; Dror, 2007) Beyond health-related issues CHAT has been used more broadly for other types of priority setting, for example identifying priorities for research. (Goold, 2018)

The application of CHAT in India demonstrates that the tool can be useful for LMICs and for rural communities. The need for the tool in the Indian rural setting arose from the gap between benefit packages available and those reflecting the priorities of the poor. The outcome of the exercise demonstrated that CHAT improved awareness of resource allocation and trade-offs among participants and, in this particular setting, enhanced both willingness to join health insurance and willingness to pay for it (Dror, 2007).

CHAT has been translated into various languages and has been adapted for computer and web-based use. (Iddo. Dror, 2007; Goold et al., 2005; Schindler et al., 2018). Because CHAT includes various rounds whereby participants first work on their own to prioritize as individuals and then in a group to make decisions together, the exercises have at times resulted in decisions being made that are not based only on personal preferences but on societal priorities and values.

In South Africa, where deliberative democratic principles prevail and the right to health is protected in The Bill of Rights, public engagement in priority setting is entrenched in various policy documents and formalised in the National Health Act, which makes provision for the establishment of community health committees, hospital boards and local health councils. (National Department of Health, 2003) While the Act stipulates that provincial departments of health must develop legislation which identifies the specific functions of the health committees, the intention is that the members of these committees should ensure community participation in the governance of and priority setting process for local clinics. (Padarath, 2008) While the political climate is in theory supportive of public engagement in priority setting at various levels, and while some Community Health Committees do exist with public representation, the role of these bodies is poorly defined, they do not function optimally and members have little input in decision making. (Haricharan, 2010) At the national level, beyond public commenting and consultations no formal structure for more meaningful public engagement in priority setting exists.

South Africa is committed to delivering quality Universal Health Coverage (UHC) over the next few years through a National Health Insurance (NHI) funding scheme. Policymakers, just like those in other countries moving towards UHC, are facing challenges in terms of what and who to cover with a limited budget, and local level decision makers may face service delivery dilemmas. Priorities will need to be set that reflect health needs, economic resources, professional and societal values, and political considerations, among others. (Hofman, 2015) The South African National Health Insurance Bill identifies cost effectiveness standards as key components for determining and refining the interventions that will be covered by NHI (National Department of Health, 2019). While cost effectiveness analyses are essential in guiding decision making, particularly for resource allocation, this process alone does not comprehensively consider social values. Public engagement on issues of decision-making and prioritization could be key to the success of setting priorities and context-specific tools to facilitate this process could be useful. Deliberative engagement methods could be useful in this regard because many of the impending coverage decisions in South Africa are complex and will require identifying and balancing individual and societal values and concerns. Context specific tools provide a potential mechanism to incorporate social values into the priority setting process in a meaningful way. The approach for developing a context specific tool is important so that the method for engagement is acceptable and reflects considerations that are important to the public and not simply pre-defined by the policymakers. These considerations should incorporate broad topics/issues as well as specific interventions to address them. A participatory approach for developing/modifying a deliberative engagement tool involving input of community members from the start could be effective in ensuring inclusive priority setting approaches that are evidence-based, ethical, legitimate, sustainable and acceptable.

To prepare for such a deliberative process in South Africa, we aimed to modify the CHAT tool for a rural community context. We selected CHAT as the deliberative engagement tool because it simulates priority setting processes and has generated positive results in its ability to engage different audiences around resource allocation decisions, particularly amongst other low-income populations and in multiple cultural settings. (Dror, 2007) Our specific aims were to a) identify health topics/ issues for the rural context and specific interventions related to these topics/issues b) estimate the cost of the specific interventions; c) convert intervention costs into sticker amounts for the CHAT game board to depict the monetary value of the interventions d) develop context specific scenario cards to demonstrate consequences of choosing interventions during the CHAT exercise, and e) translate the materials into the local language.

Other adaptations of CHAT have followed similar steps but many have not included the same degree of community and policymaker participation as our modification methodology. They have also not been documented in detail. In this paper we present all stages of the modification process, using an iterative participatory approach to adapting the CHAT tool. It is the first time CHAT has been modified for the South African context.

Methods

Study site

The CHAT tool was modified for use in the Agincourt Health and Socio-Demographic Surveillance System (HDSS) study area (https://www.agincourt.co.za/), located in

Bushbuckridge municipality in Mpumalanga Province. The site, typical of rural areas in South Africa, is comprised of 31 villages, 20,000 households and a population of approximately 111,500 (Kahn, 2012; Wariri, 2017). There are two health centers and six satellite clinics in the site and three district hospitals within 20-60km. Pipe-borne water is not available to most households and sanitation systems are poor. Electricity is available in all villages but is unaffordable for most and few tarred roads exist. Every village has at least one primary school and most have a high school, but the quality of education is poor (Twine, 2016 #30) and unemployment rates are high with labour-related out-migration commonly occurring. Life expectancy at birth is 61 for males and 70 for females (Kahn, 2012), with significant socioeconomic disparities across different indicators. (Kabudula, 2017).

Adaptation of the Choosing All Together tool- data collection

In order to modify CHAT for use in Agincourt HDSS study area we followed a 5-step approach:

1. Rapid desktop review

First a rapid review (O'Leary, 2017) of national health policy documents was conducted to identify national health topics/issues and related interventions that were a priority for the country. The starting points were the most recent national health policy documents in 2017: the transcript of the 2017 SA treasury budget speech where health spending was mentioned, and the NHI White Paper of 2015 (Department of Health, 2015). We then selected other national health documents that included any of the health topics/ issues identified in the budget speech or the NHI White paper. Eleven documents were included. Finally, we included Provincial and District level policy to identify any health topics/issues and related interventions specific to the Bushbuckridge rural context which had not been identified from the national documents. Three additional documents were included. The documents that were included in the review are shown in Appendix J. The documents were scanned in their entirety and any specific interventions related to the health topics/issues were identified and captured in a Microsoft Excel sheet.

2. Focus group discussions

Next, we conducted a focus group discussion (FGD) with each of the following groups: home-based care service providers (HBC) in the Agincourt HDSS study area, provincial and district level experts, and national policymakers, in order to identify which health topics/issues and related interventions (solutions) each group thought was important. The health topics/issues related to categories of disease (e.g. HIV/AID and TB) or focus area (e.g. mental health) or broader issues like “access”, while the interventions (solutions) related to specific activities and services that would address the health topics/issues, for example, the provision of contraceptives at schools. The first FGD (HBC FGD) comprised HBCs from Bushbuckridge who were selected from three home-based carer organizations. We selected home based-based carers as representatives of the community because in the South African context the carers are members of the communities who either volunteer or are paid a small stipend to perform basic care and support services within the home environment. The three specific organizations were convenience samples based on proximity to facilitate transport to a central location. Only HBCs who could speak English were selected but most HBCs who work in Bushbuckridge do speak some English. Seventeen people were invited, and the final group comprised 13 participants including 11 females and two males. For the second FGD (Prov/Distr FGD) 12 participants were originally invited, and final group comprised of seven (six females and one male), three were provincial-level policymakers, three district-level decision makers and one public health specialist located in Bushbuckridge. Participants were selected using purposive sampling to ensure diversity across directorates within the Department of Health (DOH). For the third FGD (National FGD) eleven people were invited, and the final group comprised eight senior national-level policymakers selected using purposive sampling to ensure a broad representation from different directorates within the National DOH. There were two females and six males.

We provided a board with a blank wheel that comprised coloured slices, and participants were given sticky notes to write down two major health topics/ issues. Each participant had an opportunity to present their topics/issues and add them to the board. Health topics/issues that overlapped were grouped together and given an overarching title (e.g., Access) by agreement amongst the participants. Additional topics/issues identified in step 1 (desktop review) that were not mentioned by the group, were described by the facilitator and the group decided whether they wanted them included. Following this, another round was conducted where participants wrote solutions (interventions) to address the topics/issues using sticky notes in a similar manner. The approach fostered strong engagement and allowed the research team to refine the health topics/issues and related interventions identified in step 1. The FGDs were recorded, transcribed and analysed qualitatively to identify topics/issues and interventions (solutions).

3. Modified Delphi

During the FGDs participants were asked to vote on each health topics/issues. Topics/issues that received the highest number of votes were included in a follow up ranking process using email to each individual participant from HBC FGD and Prov/Distr FGD in order to reconcile the differences between the FGDs and to refine the list of topics/issues for the Bushbuckridge context. Three out of six participants from the Pov/Distr FGD completed the follow up ranking while six out of 13 participants responded from the HBC FGD.

We used the Borda count method to determine the overall ranking score (Van Newenhizen, 1992). The Borda count method is considered a plausible approach in aggregating individual ranked preferences. The ranking was 1-13; we counted how many times each topic/issue was ranked 1-13 by all the participants. We multiplied this number by the ranking number (1-13) and then added this up to determine the total Borda count. The total Borda counts closest to zero were the ones that were ranked the highest. We initially selected the top 10 health topics/issues, but some were combined and/or dropped based on being too broad or already featuring within other identified topics/issues. The top seven health topics/issues were selected for the final CHAT board. The specific interventions under each of the topic/issues were refined and finalized by referring back to the qualitative data from the FGD and the desktop review.

4. Costing and allocation of sticker amounts

A total number of 70 interventions across the seven health topics/issues were costed. Costing included both program and patient-related costs. Actuarial costs were estimated by factoring in likely utilization rates.

For population estimates and epidemiological parameters we searched the literature from the Agincourt Research Unit. Ad hoc searches were also undertaken in Pubmed, Embase, and Science direct for relevant literature on population health in Bushbuckridge. The literature was collated and assessed for relevant information that could be used to populate our costing template.

Prices/unit costs of the components were collected from a variety of sources. Where cost information for the public sector was not available, we relied on the latest legal tariff document for the public sector. Public sector costs were assumed to be 70% of private sector costs. Medication costs were extracted from the South African National Health Laboratory Service Report 2018. For Bushbuckridge-specific parameters we relied on District level policy documents. Cost components and unit costs were developed based on researching existing programs that offered similar interventions. For information on costs of education and information provision we relied on expert consultations with stakeholders at the National Department of Health and with non-governmental organizations who have extensive experience in public awareness campaigns.

An Excel sheet was developed in Microsoft Excel to aggregate cost components. Interventions were expressed as a percentage of total costs and were converted to a relative number of stickers. Our starting point was 0.5% =1 sticker using an existing actuarial model developed by Milliman (www.milliman.com), an international actuarial company that has experience in the adaptation of CHAT, but some allocations were revised based on the judgement of the authors. This was reasonable because the costing exercise already relied on some assumptions due to lack of data and it was important that the final sticker value represented the relative costs of interventions as accurately as possible. Where expert opinion was needed in order to verify the relative costs, we reached out to individuals who were familiar with these costs. The stickers represented the monetary resources that would be required when specific interventions were selected. An overview of key data categories and sources are shown in Table 2 in chapter 3.

Interventions were grouped together and categorized using the common classification of level of care for health interventions used in South Africa: Health promotion, prevention, diagnosis (screening), treatment, rehabilitation, and palliative care (National Department of Health, 2003). Where categories overlapped, they were merged (e.g. prevention and screening).

5. Development of final CHAT SA board and supporting materials

The final CHAT SA board was developed based on the results from the steps above and was translated into the most widely spoken vernacular language in the study area (Xitsonga). The icons and design elements were developed in conjunction with a medical artist at the National Institute of Health in the U.S. (Figure 2, page 50).

A user manual was also developed which explained each category of intervention in detail by listing the specific interventions as well as context specific scenario cards to demonstrate the consequences of choices made during the CHAT exercise. These cards were developed drawing on the qualitative data that emerged from the FGD with the home-based carers to ensure the scenarios were appropriate for and relevant to the context. The materials were translated into the local language of Shangan and were checked by two individuals familiar with this language.

CHAT SA was tested with a group of 11 community members (nine females and two males) from Bushbuckridge. This test phase was carried out in order to observe how participants interacted with the tool and the supporting materials and to ensure the tool allowed for meaningful rationing considerations. Materials were adjusted slightly and finalized post the test.

Data analysis

Data were analysed using thematic content analysis for the desktop review and qualitative analysis for the FGDs. Initial themes were developed by identifying the topics/issues that emerged as priorities from the Budget Speech and NHI White Paper (Department of Health, 2015; National Department of Health, 2017). Following this, the policy documents were reviewed to identify themes (topics/issues) that related to those from Budget Speech or NHI White Paper as well as any that were specific to Bushbuckridge municipality or Mpumalanga Province. Codes were reviewed by all authors. The FGDs were recorded, translated and transcribed in English. Data were analysed qualitatively using thematic coding and codes were reviewed by all authors. For the FGDs we first identified themes that corresponded with those from the desktop review then identified any new topics/issues that emerged as separate themes. Sub-themes were developed to identify specific solutions/interventions under each theme and were classified according to promotion (education); prevention; diagnosis (screening); treatment; rehabilitation; palliative care

Results

Desktop review

The desktop review initially highlighted 12 broad health topics/issues. These were maternal and reproductive health; neonatal and child health; school health; mental health; disability and rehabilitation services; elderly health; HIV/AIDS and TB; non-communicable diseases; palliative services; emergency services; violence and injury; and adolescent and youth health.

Focus group discussions

Some common themes emerged across all FGDs, some of which overlapped with the topics/issues identified from the desktop review. These included maternal, neonatal and reproductive health (including teenage pregnancy); HIV/AIDS and TB; and non-communicable diseases including diabetes, hypertension and cancer.

The home-based carers spent a considerable amount of time speaking about HIV related issues. They perceived that there were an increasing number of people living with HIV, with HIV positive babies still being born. They noted as reasons for this non-adherence to treatment, the lack of condom use, and a fear of disclosing HIV status to partners, family and health care providers.

One of the participants said:

> *"The big problem that we have is that HIV is too high. Men don't want to go to the clinic for blood tests and they don't want to use those condoms".* (HBC FGD, P3)

Another participant expressed that:

> *"We have many people who are defaulting nowadays…by the time they will go to the clinic, you will find that their body soldiers are down. They don't want to take the treatment in a proper way and after they die."* (HBC FGD, P5)

The district/provincial experts also highlighted HIV/AIDS as an issue and in particular adherence to treatment, as expressed by one participant:

> "*We have very big problem with the issue of adherence on treatment…most of them are given the instructions on how to adhere to the treatment, most of them don't adhere to treatment completely"* (Prov/Distr FGD, P7)

The national policymakers considered HIV and TB an issue too, especially among young women as expressed by one of the participants:

> *“We don`t seem to be winning in reducing HIV infections in young women despite our many interventions to try and prevent those infections. And they have a major impact on the health of the women and the children of the country.”* (National FGD, P9)

Some specific solutions (interventions) that were mentioned under the theme of HIV/AIDS included education at the community level, making testing services youth friendly and enhancing monitoring of treatment adherence among others:

> *“We should strengthen our youth health services [to address HIV and teenage pregnancy].” (HBC FG, P5)*

> *“For non-adherence, we need systems… Better systems which will help the monitoring.”* (Prov/Distr FGD P4)

Maternal and neonatal mortality was discussed as another big issue alongside teenage pregnancy across all groups. There was an overwhelming concern that sex education was not effective for young people. One of the home-based carers said:

> *“Teenage pregnancy [is an issue]. You find that young woman are falling pregnant. Young people don’t listen to sex education…We don’t understand why and where the problem is.”* (HBC FGD, P12)

The lack of provision of contraceptives at schools was also a concern:

> *“We have school health services but then the policy says you cannot give it [contraceptives]... to me it is like raising the demand and not supplying.”* (Prov/Distr FGD P5)

Amongst the national experts there was agreement that maternal and neonatal mortality were issues and that teenage pregnancy was an issue in and of itself. These participants also viewed child health as related to maternal health. One of the experts said:

> *"High maternal mortality rates [is an issue], and kids without moms are more likely not to survive and certainly not to thrive. So, there is an implication not only for the mom, but the entire family."* (National FGD, P7)

Specific solutions (interventions) related to this theme included community dialogues around education, strengthening of youth health services and provision of contraceptives at schools:

> *"If the schools policies can be changed that whenever we visit the school with the school health nurses, it is better to show them all the contraceptives so that they can be aware."* (Prov/Distr FGD P7)

A further issue identified in all three FGDs was non- communicable diseases (NCDs), and that prevention was important but not as effective as it should be. One of the provincial/ district experts said:

> *"I think the growing burden of NCDs is something that really is a big issue for all of us."* (Prov/Distr FGD, P3)

One of the home-based carers expressed concerns specifically about the high prevalence of diabetes and that by the time individuals are diagnosed it is often too late.

> *"Nowadays many people are dying of sugar diabetes. The problem is that this illness is hiding and by the time they find it, it is too late."* (HBC, FGD, P4)

Similarly, one of the national experts said:

> *"[There is] an explosion of NCDs, and so it is impacting on health services in a big way and if you don`t pick them up early or prevent them then we really do fear that it is going to overwhelm the health service."* (National FGD, P2)

Solutions for NCDs that were mentioned included mobile messaging, better education at community level, vegetable gardens and others:

> *"We used to have person who was responsible to teach people on how to do gardening… [this] would be a good idea [for NCDs]"* (HBC FGD, P3)

Across all groups there was a general understanding of social determinants and the impact on health. The home-based carers spent some of the time speaking about issues of poverty specifically and how this impacts health in many different ways:

> *"There are people who are still suffering [from poverty]. Our youth are not working... They are relying on child grants. The other thing that they are doing is selling themselves to men... If you ask them, why are they doing this they will tell you that they want money to help their children. In that way they forgot about the illnesses that we have nowadays."* (HBC FGD, P5)

This was similar to what some participants among the provincial/district experts thought:

> *"I was looking at the social determination of health and what are the problems we are facing as the community… when you are unemployed, the issue of poverty comes in, [that is linked to] the issue of the disease of lifestyle…because when you are poor…you eat whatever comes your way without choosing and [it impacts] HIV… if you are poor being a woman, it is difficult for you to negotiate for condom usage."* (Prov/Distr FGD, P2)

In terms of solutions for social determinants, while the HBCs did discuss some interventions to address poverty specifically, the Prov/Distr experts noted that this topic was much broader and not within the remit of the Department of Health:

> *"That [social determinants] is a much broader area…It is actually at a different level." "It is not our competence."* (Prov/Distr FGD P1)

One issue that was particularly important to the home-based carers and the provincial/district level experts and was discussed at length was access to services, which included distance from clinics, transport issues, long queues, staff attitudes, and shortage of nurses. A considerable amount of time was spent discussing these issues during both FGDs.

One of the home-based carers expressed that:

> "… *In our clinics there is a shortage of staff. You can go there early in the morning but you can go home without getting a service. You can find that there is only one nurse who is servicing everything. [There is also] shortage of health facilities [including] mobile clinics. Some of us live far from our clinics. If we want to go to the clinics we have to get transport and we don't have money."* (HBC FGD, P5)

Although there has been some recognition by the government of access issues and some solutions have been created including mobile clinics, the participants highlighted that this type of intervention is now facing its own implementation and, in turn, access issues.

Another home-based carer said:

> *"You will queue for a long time. Many people are dying in the queue at the clinics and hospitals. Others are giving birth on the bench while in the queue, she will be attended by the time they see the baby coming out…The government must build health centres so that they operate day and night. This can reduce the total number of those who are collecting treatment and queueing for the whole day."* (HBC FGD, P7)

The provincial/district experts also viewed access as an issue. Their sentiment was that number of facilities was not the problem but rather skilled personnel within the facilities:

> *"We do have facilities, however access is not there in terms of number of facilities that have the skill."* (Prov/Distr FGD P5)
>
> *"The shortage of human resources is a real challenge"* (Prov/Distr FGD, P6)

Related to this issue of shortage of nurses was a concern about staff attitude, especially as it related to patients accessing HIV/TB medication and young girls accessing contraceptives:

> *"You can find someone who went there to collect his or her TB treatment complaining about nurses who are working slowly and again they are approaching people in a bad way."* (HBC FGD, P7)
>
> *"The nurses must stop judging people by their age. If a girl feels ready [for contraceptives], they must not judge her."* (HBC FGD, P3)

However, some of the provincial/district experts thought that the nurses are unfairly blamed for some of the issues and attributed their negative attitudes to poor working conditions:

> *"we are short staffed…and that contributes to the negative attitude from our staff members to the community. And the reason [they might have] negative attitudes might be attributed to our staff members being burnt out…Nurses are always on the firing line because of [lack of] equipment in our facilities."* (Prov/Distr P1)

Solutions offered by participants to the access issues included increasing staff, improving attitudes, monitoring and evaluation at clinic level, longer operational hours for clinics and chronic medication dispensed at community centres:

> *"The nurses must stop judging people by the age. If a girl feels ready, they must not judge her."* (HBC FGD P3)
>
> *"Treatment must be there [at the community centres] so that we don't wait for a long time. It should come in advance so that we collect it in time. This should lower the risks of defaulting."* (HBC FGD P11)

The FGDs demonstrated an overlap in topics across different groups (Table 3). There was stronger overlap between HBC FGD and Prov/Distr FGD than with National FGD. Some areas that were not identified by participants in National FGD were lack of information/education, elderly health, defaulting/ non-adherence, and in particular access, which included distance from clinics, transport issues, long queues, staff attitudes (specifically nurse attitudes), and shortage of nurses. Access seemed particularly important to local participants from the rural site. Mental health was raised by participants in Prov/Distr FGD and National FGD but not in HBC FGD. Topics that emerged from National FGD but not from the other two were disabilities, and human resources under health system. Although neonatal mortality was prioritised as a standalone issue in National FGD, it was also mentioned during the discussion under maternal mortality in the other two groups. Priority areas unique to Prov/Distr FGD were quality measures. Finally, malaria and rape/ abuse were prioritised in HBC FGD but not in the other two as a standalone issues.

For some topics/issues solutions were not written down but were discussed and the desktop review supplemented discussion with specific interventions that could address the topics/issues.

Table 3. Topics/Issues identified in the FGDs.

Topic/Issue	**HBC FGD**	**Prov/ Distr FGD**	**National FGD**
Maternal mortality / maternal and reproductive health	x	x	x
Neonatal mortality			x
Child health, including under 5 stunting		x	x
HIV/AIDS and TB	x	x	x
Social determinants	x	x	x
Lack of information / education	x	x	
Malaria	x		
Access to health services	x	x	
Rape and domestic abuse	x		

Non-compliance with chronic medication	x	x	
NCDs	x	x	x
Health system (HR, integration, material resources)		x	x
Mental health		x	x
Disabilities			x
Quality measures		x	
Elderly health	x	x	

Modified Delphi

The differences between the three FGDs were reconciled using our modified Delphi. Some topics/issues were not included in the follow up ranking that was used for the modified Delphi process as they were either too broad or fell outside of the remit of the Department of Health. Social determinants, which included issues such as poverty, unemployment, housing and sanitation, fell into this category, even though it was important to participants. During the FGD the experts had also pointed out that the issues falling under social determinants were outside of their scope. Other topics/issues that were not included as a standalone issues were the health system (including HR strategy, material resources, integration) and quality measures ones. These were very broad and some also featured within the other specific topics/issues. Table 4 shows the outcome from the follow up ranking using the Borda count. We initially selected the top 10 health topics/ issues. We then combined newborn health with maternal and reproductive health. The monitoring and evaluation topic as well as the defaulting one did not make sense to maintain as standalone topics/issues because the specific interventions within the other topics/issues incorporated much of this, so they were dropped as their own topics/ issues but were maintained as part of the detail, and incorporated in the costing, in many of the other interventions. The top seven topics/issues that remained were: maternal, reproductive and newborn health; Child Health; HIV/AIDS and TB; Lifestyle diseases; Access; Women and child abuse; Malaria. The topics/issues that were not included in the final CHAT

SA board were elderly health, mental health and disabilities as these topics/ issues received the lowest scores across all participants in the follow up ranking.

Table 4. Health topics/issues and total Borda count from follow up ranking with zero depicting the highest possible score

Health topic/issue	**Borda count**
Maternal and reproductive health (includes teenage pregnancy and adolescent health)	**44**
Malaria	**79**
Access (Improving staff attitudes[†], especially for family planning; Clinics open for longer hours; Increasing mobile clinics; Making chronic medicines available in communities)	**34**
Violence and Injury (includes rape and abuse of women and children)	**92**
Lifestyle diseases (sugar diabetes, cancer, hypertension)	**75**
Defaulting/ non adherence	**68**
Elderly health	**109**
HIV/AIDS & TB	**61**
Mental health	**124**
Monitoring and evaluation at the clinic and hospital level (includes monitoring how staff are performing)	**82**
Newborn health	**90**
Child health (includes stunting in children under 5 years of age)	**105**
Disabilities	**133**

[†] Referring specifically to nurse attitudes

Costing and allocation of sticker value

Table 5 shows the seven health topics/issues, the final specific interventions and the associated costs and final sticker values. Interventions specific to each of the topics were categorized by education; prevention (and screening); and treatment. Lifestyle diseases received a fourth category- palliative care, and woman and child abuse got management instead of prevention/ screening. Five unique categories were allocated to access. The intervention categories were treated as independent in implementation of the tool. Participants would be able to select some categories within a topic/issue without selecting others.

Table 5. Final health topics/issues, intervention categories, total cost and number of stickers allocated

Priority health area and specific interventions	**Total cost (ZAR)**	**Number of stickers***
Maternal, reproductive and newborn health		
1: Education and information	4,535,704	1
2: Prevention and Screening	81,815,414	3
3: Treatment	20,799,210	2
Child (<5 years) health		
1: Education and information	4,249,151	1
2: Prevention	13,535,105	1
3: Treatment	1,162,395	1

HIV&TB		
1: Education and information	3,466,570	1
2: Prevention and Screening	164,039,366	5
3: Treatment (including adherence support)	323,954,107	11
Lifestyle diseases (diabetes, hypertension, cancer)		
1: Education and information	8,721,868	1
2: Prevention and screening	3,589,976	1
3: Chronic medication and adherence support	1,017,906,916	17
4. Treatment for complications and rehabilitation	62,974,407	6
5: Palliative care	5,829,201	1
Access		
1: Improve staff attitudes (especially around family planning services for adolescents) and improve management and M&E in clinics	22,535,756	1
2: Make clinics operational for longer hours	116,454,896	4
3: Increase mobile clinics	12,076,740	1
4: Chronic Medicines (ARVs, diabetes meds, hypertension meds) available at community health centres to improve adherence	74,005,752	2

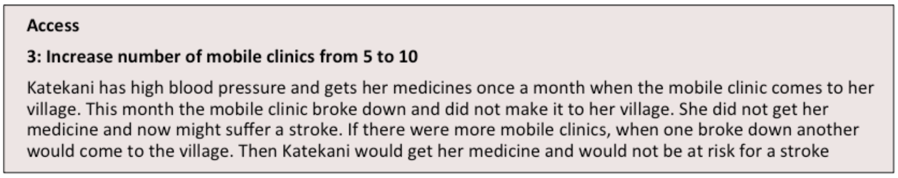
5: Increase number of nurses in clinics and more pharmacists in clinics to dispense meds so wait time is shorter	29,254,008	1
Women and Child abuse		
1: Education and information	2,376,035	1
2: Management of rape and abuse	798,874	1
3: Treatment	10,668,731	1
Malaria		
1: Education and information	104,274	1
2: Prevention and screening	39,850	1
3: Treatment	17,765	1

*starting point was 0.5% of total cost = 1 sticker but was revised based on professional judgement to ensure intervention values were accurate relative to one another

Finalisation of CHAT SA board and supporting materials

The final bilingual CHAT SA board derived from the process described here is included in appendix B. Each pie slice on the board reflects a topic/issue and was divided according to the different categories of interventions. The categories and specific interventions for each category were explained in detail in a user manual to accompany the CHAT SA board. The detail provided in the user manual made it clear that interventions did not overlap with one another.

Other materials that accompanied the CHAT SA board were the scenario cards developed for each category of interventions. Figure 3 shows an example (in English) of a scenario card under "Access".



Access

3: Increase number of mobile clinics from 5 to 10

Katekani has high blood pressure and gets her medicines once a month when the mobile clinic comes to her village. This month the mobile clinic broke down and did not make it to her village. She did not get her medicine and now might suffer a stroke. If there were more mobile clinics, when one broke down another would come to the village. Then Katekani would get her medicine and would not be at risk for a stroke

Fig 3. Scenario card under Access

Following the test phase some adjustments were made. Most of these related to clarifying content in the user manual and the scenario cards to enhance understanding. Another modification was the sticker value of treatment for lifestyle diseases. This was because this category initially required too many stickers relative to the other categories and if not chosen allowed participants to select almost all the other interventions on the board, obviating the need for priority setting once this was excluded. Due to the costing relying on high degrees of professional judgment, this adjustment was reasonable.

Discussion

The modification process of the CHAT tool for a rural South African context identified seven health topics/issues and related interventions. As the country moves towards UHC with limited resources, tough decisions will need to be made at the national and provincial level about which interventions will be covered, and at the local level, about how services will be delivered. Some of these options are included in the final CHAT SA board, which reflects both priority options of policymakers / experts and of community members and demonstrates some of the context specific coverage decisions that will need to be made. The CHAT SA is a context-specific tool which can be used for deliberative engagement and is relevant and appropriate for the rural context in South Africa. Because of the specificity of the modified tool for a rural context the acceptability of the tool will likely be high among rural community representatives.

This in turn could impact the potential success of its implementation. If implementation of the tool is successful in Bushbuckridge it has the potential to generate more meaningful public engagement and may be useful in eliciting social views around these health topics/issues by identifying priorities of the local community. This in turn has the potential to inform decision-making at the different levels with regard to a health service package.

The method used to modify the CHAT tool for a rural SA context included a high degree of community engagement and was described in detail. Most previous modifications of CHAT have followed a top down approach whereby the topics/issues for inclusion in the CHAT board are determined by experts with no or minimal community engagement. (Danis et al., 2014; D. M. Dror et al., 2007; Ginsburg et al., 2006). Some previous CHAT work has included initial preparatory discussions with experts and patient representatives to identify key issues / questions to include in the various versions of CHAT. (Goold, 2018; Hurst, 2018) The iterative participatory approach that we followed involved a high degree of consultation with experts/policymakers and community members over time, and drew on lessons from the CHAT exercise itself to engage with the different stakeholders.

The participative process we followed allowed us to identify health topics/issues and related interventions specific for Bushbuckridge community to be included in the CHAT SA tool. The difference in topics/ issues amongst the groups, specifically between national policymakers and the community home-based carers demonstrates that community engagement is important in not only identifying social values for final coverage options but also for identifying the initial topics/ issues and related interventions that should be weighed up when thinking about potential health benefits packages. This is different from the common approach to priority setting which relies on the views of expert decision makers in defining the agenda even in countries where participatory governance structures are in place. Public engagement in decision making where it exists has conventionally been implemented once the potential options have been predefined by the experts, even if at times influenced by a group of the public who has secured a voice, and with little consideration of the appropriateness of the method used. (Mitton, 2009; Weale, 2016) This paper demonstrates that if an initial inclusive and consultative approach is not followed issues like access, for example, may not be comprehensively considered ahead of time and thus may be absent from the package of potential coverage options. Issues like access, however, do not simply impact implementation but ought to be taken into account when defining health service packages and allocating the budget. The agenda, ultimately, may benefit from being set not simply by decision makers, and those that shout the loudest, but also by the broader public and the modification process we followed may be useful in this regard.

South Africa is committed to public engagement in decision making but existing structures either do not exist or do not operate as intended. This may be due, in part, to the absence of appropriate context-specific tools that facilitate public engagement in decision making around resource allocation. CHAT SA could fill this gap by strengthening existing structures like the community health committees where implementation of the tool might be helpful in ensuring the participation of the committees in the governance of and priority setting process for local clinics. CHAT SA could also be useful in initiating the establishment of new structures that make use of this tool, to ensure that the public's voice is included in decision making.

Although lessons from the modification of CHAT may be applied nationally, the tool itself was modified for a specific rural community and may not be appropriate for implementation nationally. South Africa is not homogenous with different health outcomes and challenges across its nine provinces. The CHAT SA tool while useful for a rural context may need to be adjusted for further implementation, especially in urban areas. This will require additional research locally. Herein lies the dilemma of how to develop a public engagement tool for priority setting in health that is specific enough for a local context but pragmatic enough to be applied across the country in different settings, however CHAT SA may also offer some answers. The inclusion of national policy documents and national policymakers in our study ensured that many of the national priorities featured in the modification of the CHAT tool, although these were refined for the specific rural context. The adjustment of the CHAT SA tool for different contexts in South Africa may be necessary in order to elicit broader social values but the existing modified tool can serve as a basis for this. In future potential modification processes of CHAT (for health service packages) for different South African contexts the initial steps which consisted of the desktop review of national policy documents as well as the FGD with national policymakers need not be repeated. However, it would be necessary to replicate the community engagement component in order to identify specific topics/issues and related solutions/ interventions to include in the CHAT board for the different South African contexts, as well as to ensure translation of the CHAT board and supporting materials in the local vernacular language(s). It is likely, however, that many of the topics/issues will remain because despite its heterogeneity the top causes of death are similar across provinces (Stats SA, 2018) but some service delivery challenges may differ across local contexts which ultimately impacts specific health interventions. The tool would also need to be updated every few years in the different settings in order to ensure it remains relevant as the health terrain changes.

Our modification process demonstrates that local terms that are acceptable to the community may be more important than scientific ones. We initially tested the term non-communicable diseases with the HBCs to capture the issues of cancer, type 2 diabetes ("sugar diabetes") and hypertension but the term lifestyle diseases was deemed more appropriate and acceptable. Although lifestyle diseases may have some negative connotations the community perceived it to be easily understandable. Subsequent modifications might reveal other more appropriate terms for similar categories.

A further lesson is that our modification process was resource and time intensive, and took a year to complete, and therefore may not be replicable when an urgent coverage decision is required about a specific health intervention to include in or remove from the health service package. In order to avoid this dilemma, decision makers should be encouraged to support the development of context specific engagement tools that should be used on a regular basis within the priority setting entities or institutions that evolve in South Africa. These engagement tools should be applied in determining the health service packages and in subsequent decisions about new interventions.

Limitations

A limitation of our study was that because cost data were not available for every intervention the costing component included a number of assumptions and a great level of professional judgment in developing our allocations and sticker values. We aimed to ensure the relative costs of interventions were as accurate as possible relying on expert opinion where necessary. Future modifications of CHAT for South Africa would likely need to do the same, however, as more cost effective analyses of interventions become available due to South Africa’s commitment to evidence based priority setting, more reliable costing data will be available for some interventions and CHAT modifications will be able to make use of these data. Other countries that have better costing data would not need to rely on as many assumptions and professional judgement but in settings with similar data limitations it would be important to consult with people who have experience of program costs.

Related to this, the costing of the interventions did not fully account for delivery of these interventions at high quality. Our costing model incorporated additional training, supervision and management support for interventions delivered through the health system in order to improve quality, but comprehensive quality improvements would require addressing many of the health system constraints (beyond access issues) were not feasible for the scope of this project.

Another limitation related to professional judgement was that this applied to not only costing data but also in refining some of the interventions that were ultimately included in the final CHAT board. The research team works closely with health policymakers and the familiarity may have influenced some decisions inadvertently. The decision to exclude social determinants of health as a topic seemed reasonable in light of policymakers within the DOH viewing these issues as outside their remit. A CHAT tool for SA that incorporates these social determinants of health and that informs multisectoral collaboration in priority setting could be useful in the future.

A further limitation was that the participants were skewed in terms of gender- while the national FGD featured mostly males, the majority of participants in the HBC FGD and the Prov/Distr FGD were females. If more males had been included some of the topics/issues may have differed.

A final limitation is the generalizability of the final CHAT tool. The provincial/ district experts represented a range of managers from different directorates who are responsible for dealing with a variety of health issues from planning to implementation challenges and the home-based carers are embedded within the community at the forefront of daily health issues. The inclusion of these participants in the FGDs ensured that context specific topics/issues were identified. However, other topics/issues may have emerged, or could have been ranked higher if additional participants had been included in the FGDs. This would have impacted the final topics/issues that were included in the CHAT board.

Conclusions

This research adds to the body of work on public engagement for priority setting in health and provides practical lessons for the modification of deliberative engagement tools like CHAT. This is especially relevant as countries move towards UHC and engagement methods are needed to ensure the public is included in the priority setting process. Methodologies that include participatory principles and that involve the public in setting the agenda, are useful and feasible for the modification of engagement tools like CHAT and can be applied in different country contexts in order to ensure these tools are relevant, appropriate and acceptable. In order to overcome some challenges in the modification process that generates a highly context specific engagement tool the inclusion of national policy documents and national experts should be considered in order to ensure a pragmatic approach to the application of the tool in different settings within countries. This participatory modification approach could result in engagement tools that may, through their implementation, ultimately ensure better priority setting approaches that are not only evidence-based but also ethical, legitimate, sustainable and inclusive.

Ethical Clearance

Ethical clearance was obtained from the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg, South Africa [Clearance certificate number M161009]. Free and informed consent from all participants was obtained.

Chapter 5

Tugendhaft A, Hofman K, Danis M, Kahn K, Erzse A, Twine R, Gold M, Christofides N. 2021. Deliberative engagement methods on health care priority-setting in a rural South African community. *Health Policy Plan*, 36: 1279-91. doi: 10.1093/heapol/czab005

5 Paper ii: Deliberative engagement methods on health care priority-setting in a rural South African community

Abstract

Public engagement in priority setting for health is increasingly recognised as a means to ensure more ethical, inclusive and legitimate decision-making processes, especially in the context of Universal Health Coverage where demands outweigh the available resources and difficult decisions need to be made. Deliberative approaches are often viewed as especially useful in considering social values and balancing trade-offs, however, implementation of deliberative engagement tools for priority setting is scant, especially in low- and middle-income settings. To address this gap, we implemented a context specific public deliberation tool in a rural community in South Africa to determine priorities for a health services package. Qualitative data were analysed from seven group deliberations using the engagement tool. The analysis focused on understanding the deliberative process, what the participants prioritised, the reasons for these selections and how negotiations took place within the groups. The deliberations demonstrated that the groups often considered curative services to be more important than primary prevention which related to perceived lack of efficacy of existing health education and prevention programmes in leading to behaviour change. The groups engaged deeply with trade-offs between costly treatment options for HIV/AIDS and those for non-communicable disease. Barriers to healthcare access were considered especially important by all groups and some priorities included investing in more mobile clinics. This study demonstrates that deliberative engagement methods can be successful in helping communities balance trade-offs and in eliciting social values around health priorities. The findings from such deliberations, alongside other evidence and broader ethical considerations, have the potential to inform decision-making with regard to health policy design and implementation.

Introduction

Public engagement in setting priorities for health refers to the active involvement of communities in the decision-making activities for the development of health policies and services (Florin, 2004). This approach is increasingly recognised as a means to complement standard approaches like economic evaluations and to ensure more ethical, inclusive and legitimate decision making processes (Terwindt et al., 2016). It is especially important as countries move towards Universal Health Coverage (UHC) in contexts where the demands on healthcare resources far outweigh the available resources (World Health Organisation, 2014; Weale, 2016).

The concept of public engagement is rooted in deliberative democratic principles which uphold the value of involving those whose lives are impacted by a particular decision in its development (Abelson, 2003). The inclusion of community voices in the decision-making process has potential benefits for both decision makers and communities. It ensures transparency which in turn promotes public acceptability of the decision making process and its outcomes, and increases the likelihood of successful policy implementation (Caddy & Vergez, 2001; Scuffham et al., 2014). It can also more accurately reflect communities' health needs as well as barriers and facilitators to healthcare which can lead to more appropriate resource allocation decisions (Oladeinde et al., 2020).

Different methods exist for engaging the public in priority setting but deliberative approaches are viewed as more meaningful in considering social values, balancing trade-offs and developing consensus (Carman, 2013). Some key components of public deliberation include providing participants with factual information that enables a shared knowledge base, ensuring that individuals with diverse perspectives are represented, and creating a setting where values and opinions can be voiced and challenged (Abelson, 2013). Deliberative methods encourage dialogue and debate and at times make use of tools that demonstrate the consequences of trade-offs. This is in contrast to non-deliberative approaches like surveys, opinion polling, discreet choice experiments and others where the aim is to determine “top of mind” responses and not to deeply consider and discuss issues (Solomon, 2012).

There are a number of deliberation models. Some of these include community meetings, public panels, and deliberative forums (Abelson et al., 2013). In some countries where there are formal priority setting institutions in place citizen groups play a role in the decision making process. In Thailand public representatives are involved in different stages of health benefit package development as part of the Health Intervention and Technology Assessment Programme (HITAP) (Slutsky et al., 2016). In the UK the National Institute for Health and Care Excellence (NICE) makes use of a citizens’ council of representatives of the public, which provides the public’s views on non-technical considerations for benefit inclusion by the National Health Service (NICE, 2013). This type of engagement known as “minipublics” has been used in other settings including Canada and Australia (Abelson et al., 2013). In low- and middle-income countries (LMICs) there is limited public deliberation in decision making (Alderman, 2013).

South Africa is moving towards UHC which is slated to be financed through a national health insurance (NHI) scheme. Difficult resource allocation decisions will need to be made to improve health outcomes. In the interim, the challenge of priority-setting for health continues to prevail under the existing health system structure.

Currently, the health system is divided into a public and a private sector. The public sector is poorly resourced and overburdened serving 83% of the population. The private sector serves 17% the population who derive benefit from private healthcare insurance (Competition Commission, 2019). Within the public health system, each of the nine provincial governments is responsible for service delivery decisions and the provision of healthcare services via a district-based healthcare model, but are reliant on National Government for unconditional transfers or conditional grants to finance these healthcare services (Edoka, 2020). The disproportionately low resource availability in the public sector relative to the private health sector is inequitable as more than half of financial and human resources are allocated to the private sector (Government of the Republic of South Africa, 2018).

Since 1994, South Africa is governed by its progressive Constitution which upholds participatory democratic principles and considers public engagement in the legislative process a constitutional requirement (Government of the Republic of South Africa, 1996). Various policy documents further entrench these principles. The National Policy Framework on Public Participation states that communities should influence decision making, and The Parliamentary Public Participation Model asserts that “the intention of public participation and involvement in democratic processes is primarily to influence decision-making processes that reflects the will of the people” (South African Legislative Sector, 2013; NCOP’, 2019). With regard to health, public engagement in priority-setting is formalised in the National Health Act 61 of 2003 (Amendment Act 12 of 2013), which makes provision for the establishment of community health committees (National Department of Health, 2003). The intention is that these committees ensure public participation in the priority-setting process for local clinics, but in reality, this does not happen (Padarath, 2008). At both the national and provincial/local levels any public engagement that does occur is typically a passive event. It is not deliberative in nature and does not allow for the interrogation of what trade-offs the public might be willing to make within a constrained budget.

Despite the recognition of the importance of public engagement in priority-setting for health in South Africa, there are limited tools and applications that enable a deliberative approach and where communities are able to consider resource implications and balance individual and societal values in reaching consensus regarding trade-offs. This paper focuses on the application of a modified deliberative engagement tool in a South Africa rural setting. It explores the group deliberations, what issues were prioritised by community members, the reasons for these selections and how negotiations took place within the groups. This is the first time a deliberative engagement tool has been implemented in South Africa which considers health priorities and trade-offs in the context of limited resources.

Methods

Study site

The Agincourt Health and Socio-Demographic Surveillance System (HDSS) study area (https://www.agincourt.co.za/) is located in Bushbuckridge municipality in Mpumalanga Province. The area is typical of rural South Africa as it fits into the definition by the Comprehensive Rural Development Framework of

"settlements in the former apartheid homelands, with no major economic base apart from migrant labour and remittances, typified by poverty and underdevelopment and where traditional authorities operate a land tenure system" (Twine et al., 2016)

It has a population of approximately 120,000 and life expectancy at birth is 61 for males and 70 for females (Kahn, 2012). There are two health centres, six satellite clinics and three district hospitals within 20-60km from the villages. Sanitation systems are inadequate with pipe-borne water unavailable to 47% of the 20,000 households (Agincourt Health and Demographic Surveillance System, 2020). Electricity is unaffordable for most and few tarred roads exist. Every village has at least one primary school and most have a high school, but the quality of education is poor (Twine, 2016) with 54,9% of adults having passed matric. Unemployment rates are high, and many households are dependent on government grants (Agincourt Health and Demographic Surveillance System, 2020).

The deliberative engagement exercise

The CHAT (Choosing All Together) tool, which was originally developed by the US National Institutes for Health and Michigan State University, is a game-like exercise and aims to facilitate a deliberative and interactive process that encourages group decision making as participants grapple with trade-offs (Goold, 2005). During the exercise a trained facilitator guides participants through different rounds where they distribute a limited number of stickers on a board as they select from a range of options. The stickers, which represent the available budget, are only able to cover approximately 60% of the options on the board

The tool was modified for use in Bushbuckridge. This modification process included an iterative participatory approach that relied on policy analysis and engagement with experts and community members to identify health topics and related interventions specific for the Bushbuckridge context. This process is described in detail elsewhere (Tugendhaft, 2022) The outcome of the modification process was a context specific bilingual CHAT board which included seven health topics/issues and costed options within each topic/issue to select from as part of a health services package through the allocation of funds represented by stickers.

The CHAT SA board is shown in appendix B and the health package options are summarised in table 6. The board is divided into different pie slices with different icons for each slice. Each pie slice represents a health topic or issue. The slices are further divided according to different categories of interventions. Interventions were grouped together and categorized using the common classification of level of care for health interventions used in the South African health system: health promotion, prevention, diagnosis (screening), treatment, rehabilitation, and palliative care (National Department of Health, 2003; Department of Health, 2015). The access slice included five unique categories. The total cost of the package of interventions is approximately R2 billion ($123 million) represented by 67 holes and each category of interventions per health topic/issue has a specific cost depicted by the sticker holes. Participants received 35 stickers which represented the funds they had available to allocate and that were able to cover 52% of the options on the board. This allocation was based on a starting point of 60% of stickers drawing on past CHAT exercises and was revised to allow for more meaningful rationing in the context of this specific board.

Table 6. Topics/issues and specific interventions of the CHAT board

Mother, new-born and reproductive health (MNRH)
1: Education and information
Two-month long media campaign on antenatal care (Agincourt Health and Demographic Surveillance System)
Two-month long media campaign targeted at adolescents
Sex and reproductive education at schools
Mobile messaging for pregnant women
2: Prevention and Screening
Cervical cancer screening (three per lifetime)
HPV vaccine at schools
Contraceptive provision at schools
Improve and provide more ANC- training of healthcare workers in basic ANC
Exclusive breastfeeding – promotion and access to lactation specialists
Complementary feeding- demonstrations
3: Treatment
Expanded services for termination of pregnancy - make available in communities.
Dedicated obstetric ambulances
Maternity waiting homes
Labour and delivery management
emergency care for mothers and newborn
Child health
1: Education and information
media campaigns for immunisation and handwashing
workshops on child health
2: Prevention
Hand washing promotion in community
Provision of food supplements for malnutrition & education
Immunisations (PHC level)
3: Treatment
ORS for diarrhoea

Oral antibiotics : case management of pneumonia in children
HIV/AIDS &TB
1: Education and information
2 months long media campaign
1 education workshop per year in every secondary school
2: Prevention and Screening
Increase provision of condoms
Youth friendly MMC services - include school friendly hours
testing for HIV exposed babies
HIV Counseling and Testing
Making HIV Counseling and Testing youth friendly (training; extra hours)
3: Treatment
ART & mobile messaging reminders for adherence
Prevention of mother to child transmission of HIV (ARVs and breastfeeding choices)
TB treatment
Home based care
STI treatment
Youth Care Club
Lifestyle diseases (diabetes, hypertension, cancer)
1:Education and information
Two month long media campaign on NCDs
Educational workshop on lifestyle diseases at community level
2: Prevention and screening
School vegetable garden
Increase screening and counselling in communities
3: chronic medication
Diabetic medication
hypertension medication
Mobile messaging for adherence
4. Treatment for complications and rehabilitation
Retinopathy
Dialysis
Amputations
Chemotherapy and radiation
Rehab session for stroke patients
5: Palliative care
Palliative care (in-patient)
Palliative home based care

Access
1: Improve staff attitudes[‡] (especially around FP services for adolescents) and improve management and M&E in clinics
2: Make clinics operational for longer hours
3: Increase number of mobile clinics from 5 to 10
4: Chronic Medicines (ARVs, diabetes meds, hypertension meds) available at community health centres
5: Increase number of nurses in clinics and more pharmacists in clinics to dispense meds
Woman and Child abuse
1: Education and information
Education/ life skills for children and adolescents, workshops on gender
Media messaging
Training and support workshops for families
2: Management of rape and abuse
Care and support programmes, including counselling and comfort kit
Training of nurses
3: Treatment
treatment of injuries at clinics
PEP, 4 weeks PEP
Malaria
1: Education and information
Annual education campaign
2: prevention and screening
ITN & indoor residual spraying
screening at clinics
3: Treatment
antimalarial medication for uncomplicated cases

The categories and specific interventions for each category were explained in detail in a user manual written in simple language in the local language (Shangan) that accompanied the CHAT SA board. The detail provided included descriptions of the interventions, delivery mechanism and the cost of the intervention in sticker value. The manual made it clear that

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[‡] Referring specifically to nurse attitudes

interventions did not overlap with one another and were independent of one another- i.e. one category of intervention (e.g. treatment for Malaria) could be selected without selecting another category under the same topic (e.g. prevention and screening for Malaria).

Participants

Sixty-three individuals participated in seven group deliberations using CHAT, with 6-11 individuals in each group. Table 7 shows the group composition in terms of age and gender of the 9 groups.

Table 7. Group composition in terms of gender and age

	G1	**G2**	**G3**	**G4**	**G5**	**G6**	**G7**
Male	1	3	3	1	7	5	7
Female	5	5	8	10	4	4	0
Age range in years	37-62	30-67	30-55	20-28	20-42	40-66	48-67
Mean age in years	42	43	39	23	25	52	55

Sampling and recruitment

Purposive sampling was used to include participants from a range of six villages. These villages included three with clinics in the village and three without; three with tarred roads and three with dirt roads in order to ensure inclusion of villages with different levels of development as well as different barriers to accessing healthcare. The participants were selected to ensure a mix of females and males in each of the groups except for two which included one all male group and another group which included predominantly females. The participants were also selected based on age in order to ensure a mix of age ranges. Seventy participants were recruited face to face by experienced fieldworkers who explained the purpose of the study and invited them to participate. The final number of participants comprised 63.

Study procedures

During each of the 7 groups, after the facilitator explained the board, participants individually allocated the stickers to the health issues and interventions that they perceived to be the highest priorities for their own family (round 1). Once this was complete the group completed a board collectively in terms of their priorities for the entire community of Bushbuckridge (round 2: group round). The group rounds were led by a trained community facilitator who was guided by a detailed script (Appendix C). The groups were expected to reach consensus about how to allocate the stickers through majority vote. The entire deliberation process was audio-recorded with consent from participants. Scenario cards were used by the facilitator to assist participants in thinking through the implications of the decisions that they made. During the final round (round 3) participants were again asked to complete the exercise individually thinking about which priorities they believed were most important for their own family. The entire exercise took half a day with the deliberations during the group round taking approximately two hours to complete.

An informed consent process was undertaken at the recruitment stage. Separate consent was obtained for audio recording. Participants were given a participant number in order to maintain their anonymity.

Data analysis

This paper focuses on the verbatim transcripts from the audio-recordings of the group rounds to understand the deliberative process, what the priorities were, why some were selected over the others and how negotiations took place within the groups. The verbatim transcriptions were translated from the local language, Xitsonga, into English. Content analysis was conducted. Initial codes were developed deductively based on the health topics/ issues on the CHAT board. Sub-codes were developed based on the interventions under each health topic/issue and were classified according to promotion (education); prevention; diagnosis (screening); treatment; rehabilitation; palliative care. Inductive codes were identified through deep readings of the transcripts and definitions were developed. Inductive codes were mostly linked to the CHAT deliberative process. These codes included deliberations; trade-offs; resource allocation; and shift in prioritisation.

Codes were reviewed by a second coder and revisions were made for greater clarity through discussions. The codes were then applied systematically to all transcripts supported by MAXQDA 20.

Results

Participant Characteristics

The participants (n=63) ranged from age 20 to 67 years with a mean age of 39 years. Fifty seven percent were female and 43% male; 41% had some degree of secondary education but only 24% had completed high school (Matric). Most of the participants had a household income of R3000 ($20) or less per month with 30% receiving government grants and 37% relying on a combination of government grants and either formal or informal employment.

Table 8. Participant Characteristics

Participants characteristics (N=63)		
Participant characteristics	**n**	**%**
Age		
>35	35	56%

<35	28	44%
Gender		
M	27	43%
F	36	57%
Education		
No schooling	7	11%
Primary school	10	16%
Some high school	26	41%
Completed high school (Matric)	15	24%
Tertiary	5	8%
Household Income		
R3000 and below	36	57%
R3001-R5000	17	27%
> R5000	10	16%
Income source		
Government grants	19	30%
employment	11	17%
grants and employment	23	37%
Other	10	16%

Table 9 shows the final group choices for each health topic/issue and intervention category as well as the percentage of stickers (budget) that was required to cover each intervention category. The presence of an asterisk within the table demonstrates that the option was selected by the group or was not selected where an asterisk is absent. Every group selected a spread of some education, prevention and treatment although some treatment options were more prevalent. None of the groups selected palliative care, which only featured under non-communicable diseases (Lifestyle 5), nor did they select Access level 4 which was making chronic medication available at community health centres. Three areas that were picked by 6 of the 7 groups were treatment for HIV/AIDS and TB, prevention under child health which included food supplementation and immunisations, and Access level 3 which was increase the number of mobile clinics.

Table 9. Group choices of interventions

Health topic/issue displayed on the CHAT Board	**% of stickers (budget)**	**FGD 1**	**FGD 2**	**FGD 3**	**FGD 4**	**FGD 5**	**FGD 6**	**FGD 7**	**Total number of groups selecting the topic/issue**
Maternal, neonatal and reproductive health (MNRH) 1 (education)	1,5	*	*	*			*		4
MNRH 2 (prevention & screening)	4,0				*		*		2
MNRH 3 (treatment)	3,0			*		*			2
Child health 1 (education)	1,5			*			*		2
Child health 2 (immunisations, food parcels)	1,5	*	*	*	*	*	*		6
Child health 3 (treatment- ORS and antibiotics)	1,5			*	*		*		3
HIV/AIDS & TB 1 (education)	1,5			*		*	*	*	4
HIV/AIDS & TB 2 (counselling and testing, condoms)	8,0	*						*	2
HIV/AIDS & TB 3 (ARVs & TB treatment)	16,0	*	*		*	*	*	*	6
Lifestyle diseases 1 (education)	1,5	*					*		2
Lifestyle diseases 2 (prevention & screening)	1,5	*			*		*		3

Lifestyle diseases 3 (chronic medication)	25,0		*	*		*		*	4
Lifestyle diseases 4 (tx for complications)	9,0	*			*		*		3
Lifestyle diseases 5 (palliative care)	1,5								0
Access 1 (staff attitudes)	1,5	*		*	*				3
Access 2 (clinics open for longer)	6,0	*		*	*		*		4
Access 3 (mobile clinics)	1,5		*	*	*	*	*	*	6
Access 4 (chronic medication at community centres)	3,0								0
Access 5 (increase number of nurses)	1,5			*					1
women and child abuse 1 (education)	1,5	*		*	*		*		4
women and child abuse 2 (management and counselling)	1,5	*			*		*		3
women and child abuse 3 (treatment)	1,5		*	*	*	*			4
Malaria 1 (education)	1,5		*	*	*				3
Malaria 2 (prevention and screening)	1,5	*	*		*	*	*		5
Malaria 3 (treatment)	1,5	*	*	*	*				4

The results from the qualitative analysis help to understand the considerations behind the priorities, what types of negotiations took place, and what trade-offs were made within the groups in order to allocate the budget to a particular issue and intervention category.

Education vs prevention vs treatment trade-offs: Medicalisation of healthcare

Although all of the groups chose a spread of treatment, education and prevention options, much of the deliberations focused on the benefit of treatment options versus education and/or prevention.

Education/prevention as insufficient in leading to behaviour change

There was an overriding view across all groups that even with education and prevention programmes, disease would still be prevalent. This was influenced by the perception that existing health education and prevention programmes largely were ineffective in leading to behaviour change. In addition, many of the perceived underlying factors of ill-health, such as poor water and sanitation (and other social determinants of health), were outside of their control as individuals even where awareness was sufficient. Treatment, therefore, was considered important to address these issues.

> *"[*Community members] *are just ignoring the knowledge [on malaria] that they have and there is nothing that can change them. So…it is better we don't give education but we prevent them from dying"* (G5)

Treatment as HIV prevention, investment in future generations and to address NCD fatalities

Treatment was considered especially important when it came to HIV/AIDS and TB and NCDs. For these issues, the treatment options required significantly greater investments compared to education and prevention, but many of the groups traded off prevention and/or education for treatment. The reasons for allocating resources to treatment for HIV/AIDS included that it contributed to prevention by reducing the risk of transmitting HIV. It was also viewed by some participants as investing in future generations and supporting those who may have been infected during the perinatal period. There were also concerns around drug stock-outs and HIV treatment adherence, and an investment in treatment was viewed as a way to address these issues.

> *" I have chosen treatment for HIV/AIDS because if we can adhere to treatment, HIV cannot continue to spread and the future generation can be HIV free."* (G7)

In relation to NCD chronic medication treatment many of the groups expressed concerns about NCDs being serious and fatal without treatment. There were specific mentions of type 2 diabetes and hypertension as silent killers and treatment was viewed as a means to prevent these fatalities.

> *"…There are diseases that kill people instantly…the government needs to put a lot of money on the chronic diseases like high blood pressure… sugar diabetes etc. because their lives are at stake and if they miss taking their treatment…they are gone."* (G5)

Education for reproductive health, HIV/AIDS and violence against women and children

Despite the view of participants that existing health education did not lead to desired changes, some groups considered that it had a role to play. The issues that garnered most allocation for education were reproductive health, HIV/AIDS, and violence against women (specifically rape) and children. All these topics related to sexual practices and/or violence, some focused specifically on adolescent sexual practices, and health education was seen as important in this regard. There was an emphasis on community and family education as opposed to existing school-based programmes which were viewed as ineffective, and there was a need identified for open communication between parents and their children. Some of the groups also spoke to the need for more effective sexuality education at schools.

> *"...educate the youth in the villages [with] parents also assisting them. Some teenagers get pregnant because they get engaged in sexual activities without the knowledge and information [they need] education on the effects of unprotected sex."* (G5)

Group 3 and group 6, both mixed groups of men and women and with a mean age of 39 and 52 respectively, prioritised health education across health topics more than the other groups. Group 3 was the only group that did not select treatment for HIV/AIDs and TB, and instead chose to invest in comprehensive sexuality education. There was a deliberation about changing the selection to include treatment for HIV/AIDS & TB but the group maintained their position and noted that they would like to make a case for increasing the budget rather than forgoing sexuality education:

> *"…. I think that education is the most important thing on HIV/AIDS because people will learn and know what will lead them into contracting HIV…I think it will be a good thing if we [keep our allocation as is] and we will go back to the government and ask for more money to budget for some of the things that we think are as important"* (G3)

Sexuality education and inequitable gender norms

Across the groups inequitable gender norms were expressed, including views that women were responsible for violence perpetrated against them. In two group discussions there was a strong endorsement of rape myths, for example, that young women would not be raped if they dressed appropriately. Sexuality education was viewed as a way to ensure that young women controlled their sexuality and were less provocative towards men. This perspective was prevalent among both males and female group members. It showed that while health education was viewed as the solution to some of the issues that the community faced, the nature of the education that was proposed would endorse unequal gender power relations.

> *"...if as a mother, you can sit down with your daughters and teach them the good way to dress because they can be raped because of the way they are dressed"* (G6)

Group 7, which was the only entirely male did group did not consider violence against women and children an issue at all and did not select anything under this topic.

> *"I did not choose this health service because as men we are known to be the abusers and we are not abusing anyone. It's just that [young girls] love money too much and they can even lie and say that they have been raped meanwhile they only want money."* (G7)

Education to improve treatment efficacy

Another reason why some groups selected education, particularly for issues such as HIV/AIDS and malaria, was to improve treatment efficacy. Delays in diagnoses were viewed as one of the reasons why treatment started late, often resulting in poorer outcomes. Education was viewed as important to address these issues- participants wanted better information about symptoms to ensure early help-seeking with a quicker diagnosis and initiation on treatment.

> *"They can read the signs and know what to do.. they can go to the clinic while there is time than to delay going to the clinic to get the treatment. So education is good so that people will be able to go to the clinic and get the treatment in case they have malaria."* (G5)

HIV/AIDS & TB Treatment and NCD Treatment trade-offs

In addition to the trade-offs between primary prevention interventions and treatment interventions, among some of the groups there were explicit trade-offs that took place between treatment for HIV/AIDS and TB and treatment for NCDs (which included two separate categories of chronic medication and treatment for complications).

Treatment for HIV/AIDS and TB required 16% of the budget and was selected by all groups except for one (group 3). Treatment for NCDs required the highest percentage of the budget (25% for chronic meds and 9% for treatment of complications) and was prioritised by all groups- 4 of 7 selected chronic medication and the 3 that did not select chronic medication selected treatment for complications. These three groups traded off their NCD chronic medication investment for treatment for HIV/AIDS and TB and compromised by investing in treatment for NCD complications so that they were able to include a treatment option within this topic that was less costly

Other groups (3 of 7) that selected both chronic medication for NCDs and treatment for HIV/AIDS (36% of the budget combined) traded off other interventions, specifically within primary prevention and education across categories.

The reasons given why groups prioritised HIV/AIDS & TB treatment over chronic medication for NCDs were based on age. HIV was perceived to be a disease that affects younger people while NCDs were viewed as more common among older people. Another factor was whether treatment was viewed as able to cure/control disease. TB was viewed as curable while NCDs were not. There was a perception among some of the groups that NCDs lead to death even where medication is available.

> *"People who are living with HIV are able to live for a long with the treatment…and as for sugar diabetes, they don't live for a long time even when they are taking the treatment. Once you have been diagnosed with sugar diabetes, you will die; there is no other way"* (G4)

One group (group 4) debated at length selecting chronic medication for NCDs, but later on when discussing HIV/AIDS treatment made a strong case for removing the amount allocated to chronic medication for NCDs and giving it to treatment for HIV/AIDS.

> *"I want treatment [for HIV/AIDS]. I understand that we can take our money from other areas because we are still budgeting…Why don't we take the money that we have put*

> *on treatment for lifestyle diseases and put it on the treatment for HIV/AIDS and TB." (G4)*

The group finally unanimously agreed on reallocation of funds. Their compromise was to allocate a percentage of their budget to treatment for complications under NCDs, which included amputations, treatment for strokes and chemotherapy.

Healthcare access trade-offs

Access to health care was considered important by all groups and was cross cutting. Access issues were predominantly discussed in relation to improving treatment interventions but were also considered important for family planning and antenatal care. Trade-offs primarily took place between the different categories under access as opposed to trading-off between access and other health issues. The top three priority issues included increasing the number of mobile clinics (selected by 6 of the 7 groups), longer operating hours at clinics (4 of 7) and improving nurse attitudes (3 of 7). Only one group selected increasing the number of nurses and pharmacists in clinics, and none of the groups invested in making chronic medications available at community centres.

Mobile clinics and longer hours to improve adherence to medication and healthcare access

Mobile clinics and clinics operational for longer hours were prioritised to improve adherence to chronic medication and ARVs, and to increase healthcare access for the elderly and disabled, especially in villages without clinics. Extended opening hours would overcome the challenges of individuals requiring emergency treatment after hours, which was compounded by limited household income which affected access to transport.

> *"The number of mobile clinics [should] be increased because some families are...unable to pay the taxis to travel to the clinic. Some families are getting by*

> *through the social grants money and it is not enough. …It is a challenge if there is a member of that household that is ill and they are living under poverty, how can they travel to the clinic."* (G3)

> *"if there were clinics… and they were operating for 24 hours, at least [women] will go there to give birth …some lose their babies because they have to travel a long distance to the hospital.*" (G5)

There were some discussions about the need for primary health care clinics in every village, even though this was not an option on the CHAT board. One group (group 5) discussed investing in additional clinics instead of mobile clinics. However, there was recognition that this would likely be unaffordable for the entire community of Bushbuckridge and so mobile clinics were viewed as an interim solution

Nurse attitudes as a barrier to healthcare access

Nurse attitudes were perceived as barriers to HIV testing and treatment, which was related to stigma, and to family planning and ANC services, especially for young women and teenagers.

> *"The nurses have their own gestures that they use to show each other that you are HIV positive. And for some people who are HIV positive… they have the fear that the people working in their local clinic will disclose their health status to other people."* (G1)

Group 4 which was a younger group (20-28 years) with 10 women and only one male was especially concerned about the nurse attitudes:

> "*These nurses don't know what they want us to do because if we go to the clinic for contraceptives, they tell us that we are still young for someone who is sexual active…And again if we go to the clinic for ante-natal care, they also tell us that we have fallen pregnant at an early age because we were not using the contraceptives; what do they want us to do exactly?" (*G4)

Improving nurse attitudes and increasing the number of mobile clinics did not require a substantial amount of the budget (both 3%) but participants commented that they were willing to spend even more on these areas.

Discussion

The implementation of the CHAT SA tool in a rural setting in South Africa demonstrates that the groups were able to engage with various trade-offs required when developing a health services package within the context of resource constraints and reach consensus on priorities. There is evidence on expert opinions for priorities for UHC in South Africa, and limited work on community views on health system challenges to improve public sector services under NHI (Honda et al., 2015; Mathew & Mash, 2019). This is the first time a deliberative approach was used to consider the views of the public with regard to the design of a health services package under UHC and in the context of a constrained budget. The priorities and the justification behind the choices that emerged from the CHAT exercise reflect some of the social values of the community and could be useful in informing decisions about health services as South Africa moves towards UHC.

A predominant theme across groups was the medicalisation of healthcare and prioritisation of curative services over primary prevention options, and the need to invest in improvements of the former. This was linked to perceived inefficiencies in existing health programmes and services, which result in treatment delays and are compounded by barriers to access. The community priorities were also related to perceptions about disease progression. In relation to HIV/AIDS, there was an understanding and appreciation for the ability to continue to live a long life by adhering to ART, yet with regard to NCDs there was a belief that they shortened people's lifespan even with treatment. The misconceptions related to NCDs may be influenced by the fact that people with HIV/AIDS usually present at a much younger age than those with NCDs. These misconceptions are also likely influenced by delays in screening and diagnoses of NCDs which ultimately results in limitations regarding treatment efficacy in South Africa, as well as a historical country level prioritisation of HIV/AIDS testing and treatment with limited resources having been available for other illnesses like NCDs (Madela et al., 2020; Schutte, 2018). This speaks to the need to tackle health system failures not only to improve health outcomes but also to encourage deeper understanding of disease and illness, which in turn is related to the shortcoming of current awareness programmes. This also supports the more recent approach of investing in NCD prevention and treatment.

None of the groups focused solely on health education and prevention services. Existing health education programmes were viewed as often being ineffective in leading to behaviour change. The finding indicates either a disjuncture between current prioritisation and community needs or that implementation of existing policies and programmes are ineffective at the community level. Where primary prevention was considered important it related predominantly to community-based sexuality education or was directly related to improving treatment efficacy and investing in children as the future generation through interventions like immunisations. This demonstrates that more of an emphasis should be placed on community level programmes and that children are valued as important members of the community to preserve the future.

Access issues were the backbone of the deliberations and intertwined specifically with treatment efficacy considerations. Because the groups viewed health as being medicalised, access to treatment was important in order to improve these outcomes. Access issues were also linked to poverty especially with regard to transport costs to distant clinics and investing in mobile clinics was viewed as a way to address these challenges. None of the groups selected chronic medication availability at community health centres which is a current policy initiative in the country. South Africa is committed to more effective dispensing of chronic medication (including ARVs) often through community health centres in rural areas (Health Systems Trust, 2016). While the need for improved chronic medication provision is clear, the barriers to this type of service and the preference for allocation of resources toward other interventions like mobile clinics may have been overlooked by policymakers in the absence of meaningful public engagement. Some of these barriers may be due to specific issues that were raised by the groups which included stigma and discrimination that still prevails in relation to HIV/AIDS and the need for confidentiality around HIV testing and treatment (Pantelic et al., 2020). This may be easier to ensure through alternative collection points like mobile clinics, as opposed to community health centres.

While violence against women and children was recognised as an issue by most of the groups, gender attitudes of all groups, especially the all-male group, were untransformed with blame placed on women. This was specifically stated in relation to the manner in which women or young girls dress, which is often used as a justification of violence against women and perpetuates hegemonic masculinity (Smith et al., 2015). This prevailing view among the groups demonstrates that the findings of this study, as well as any public engagement process should be interpreted within a broader Human Rights lens which values ethical considerations like equity.

The groups also did not invest in palliative care but broader ethical consideration like ease of suffering or dying with dignity would be important to consider for any context. This speaks to the need for priority-setting processes to incorporate public engagement with multiple community groups and to be governed by broader ethical consideration that may not emerge within the social values of the groups (Clark, 2012). Ethical frameworks for priority-setting alongside public engagement can be helpful in this regard.

South Africa is committed to public engagement in priority-setting for health, yet the views of communities are in reality not considered in policy and programme development which largely involves top down decision making (Gilson & Daire, 2011). The implementation of the policies in turn is not evaluated in terms of responding to community needs. This perpetuates a cycle of policies and programmes that are often inappropriate and ineffective (Maphumulo, 2019). While South Africa's National Parliamentary process includes public consultations and while there are mechanisms in place at the local level, like the Community Health Committees, these engagements have not been deliberative nor about what trade-offs the public would be willing to make within a constrained budget. The implementation of CHAT in a rural setting in South Africa demonstrates that deliberative engagement methods can be successful in helping communities balance trade-offs and in eliciting social values around health priorities. This is similar to findings from previous CHAT exercises which demonstrated that decisions were made that were not only based on personal preferences but on societal priorities and values (Dror, 2007; Danis, 2010; Schindler, 2018).

Limitations

This study has several limitations. The way in which we designed the CHAT board meant that the intervention categories were independent of one another for example, treatment for complications under NCDs could be selected without selecting chronic medication which in turn did not allow for the cascading impact on cost which would be a consideration in a real life context. Our design was intentional in order to allow participants to prioritise between primary prevention and curative services but in doing so the true cost of the one option without selecting the other is not reflected. Other CHAT exercises have provided levels contingent on others, but it is still difficult to reflect changes in costs of some interventions after selection of others. Any future virtual design of CHAT may benefit from including a feature that allows for the cost of interventions to be modified in real time as other interventions are selected. In addition, choices were constrained by prior selection of what is on the CHAT board. Our participatory methodology for modifying the CHAT board resulted in some topics/issues being excluded, for example mental health care, despite the fact that this is widely recommended. On the other hand, the benefit of CHAT is that there is room for deliberation so that expression of group preferences is not totally dictated by what is offered on the board, this was evident as the groups discussed the need for permanent primary health care clinics even though this was not an option on the board.

An additional limitation is that although the costs of interventions is captured by the sticker hole allocation on the CHAT board, cost effectiveness information is not depicted. The deliberations that result are, therefore, influenced by the costs of the interventions and the views of participants but not cost effectiveness data. Prevalence information is also not provided but the topics and interventions that were included in the CHAT board were reflective of the disease burden in Bushbuckridge.

A further limitation is that CHAT is a time intensive exercise and in order for it to influence priority setting it would need to be implemented with additional “publics” or supplemented with a broader engagement strategy that makes use of mechanisms like online democratic forums. This speaks to the need to develop engagement tools that are a key component of priority setting institutions and can impact decision making in a timely fashion.

Another limitation is related to reconciling differences among the groups. While there were some overarching themes and clear convergence of priorities across groups there were also some divergent views, for example the importance of sexuality education. It is not clear if these divergent views represent entrenched differences in social values, personal experiences or conceptualisation of issues but this could be further explored with additional CHAT exercises.

Conclusion

As South Africa moves towards UHC, economic evaluations will be critical be important in guiding difficult coverage decisions. However, broader social values will need to be considered in order to ensure these decisions are appropriate. In addition, any priority-setting process for health would benefit from meaningful public engagement to enhance its legitimacy. While some criticism of public engagement focus on the complexity of resource allocation decisions and the inability of the lay public to grapple with such decisions (Carpini, 2004) the implementation of CHAT SA demonstrates that communities can appreciate the concept of trade-offs within the context of limited resources and that there is value in engaging with communities for priority-setting for health. The findings from such deliberations, alongside other cost effectiveness evidence and broader ethical considerations has the potential to inform decision-making at the different levels with regard to health policy design and implementation. This ultimately can lead to improved priority-setting processes so that health outcomes are more successful.

Chapter 6

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Moving towards social inclusion: Engaging rural voices in priority setting for health.
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6 Paper iii:

Moving towards social inclusion: engaging rural voices in priority setting for health

Abstract

Background: Achieving universal health coverage (UHC) in the context of limited resources will require prioritising the most vulnerable and ensuring health policies and services are responsive to their needs. One way of addressing this is through the engagement of marginalised voices in the priority setting process. Public engagement approaches that enable group level deliberation as well as individual level preference capturing might be valuable in this regard, but there are limited examples of their practical application, and gaps in understanding their outcomes, especially with rural populations.

Objective: To address this gap, we implemented a modified priority setting tool (Choosing All Together- CHAT) that enables individuals and groups to make trade-offs to demonstrate the type of health services packages that may be acceptable to a rural population. The paper presents the findings from the individual choices as compared to the group choices, as well as the differences among the individual choices using this tool.

Methods: Participants worked in groups and as individuals to allocate stickers representing the available budget to different health topics and interventions using the CHAT tool. The allocations were recorded at each stage of the study. We calculated the median and interquartile range across study participants for the topic totals. To examine differences in individual choices, we performed Wilcoxon rank sum tests.

Results: The results show that individual interests were mostly aligned with societal ones, and there were no statistically significant differences between the individual and group choices. However, there were some statistically significant differences between individual priorities based on demographic characteristics like age.

Discussion: The study demonstrates that giving individuals greater control and agency in designing health services packages can increase their participation in the priority setting process, align individual and community priorities, and enhance the legitimacy and acceptability of the decision-making process. Methods that enable group level deliberation and individual level priority setting may be necessary to reconcile plurality. The paper also highlights the importance of capturing the details of public engagement processes and transparently reporting on these details to ensure valuable outcomes.

Keywords: social inclusion, rural health, priority-setting, public engagement, South Africa

Public Contribution:

The facilitator of the CHAT groups was a member from the community and underwent training from the research team. The fieldworkers were also from the community and were trained and paid to capture the data. The participants were all members of the rural community- the study represents their priorities.

Introduction

The 2030 Agenda for Sustainable Development is driven by the global commitment to “leave no one behind” and “put the furthest behind first” (United Nations, 2015). This agenda includes promoting social inclusion and prioritising the poorest and most disadvantaged groups in society (United Nations, 2016). The sustainable development goals (SDGs) in turn were developed to address inequities and SDG 3 aims to “ensure healthy lives and promote well-being for all”(United Nations, 2015). As such, there has been a global commitment towards Universal Health Coverage (UHC) to ensure everyone has access to quality healthcare without financial hardship. This is more pertinent in rural areas where 80% of people living in poverty reside and health inequities prevail (UN, 2021). It is well established that people in the lowest socio-economic groups, many of which reside in rural areas, are more vulnerable to disease and illness (“illness vulnerability") and experience greater lack of access to health care (“access vulnerability”), especially in low- and middle-income settings thereby leading to greater social exclusion (Mangundu et al., 2020; United Nations Department of Economic and Social Affairs, 2016; Vergunst et al., 2016).

While social exclusion is a contested term, it broadly refers to a state where individuals are unable to participate fully in society due to lack of access to material resources (income employment, housing) and services such as healthcare (United Nations Department of Economic and Social Affairs, 2016). It also extends to a lack of voice in decision making that impacts their lives (United Nations Department of Economic and Social Affairs, 2016). Rural populations often experience greater social exclusion due to high poverty and unemployment rates, and barriers to accessing services including healthcare. These populations are also often excluded from decisions that affect their lives including those related to health services (Bourke, 2022). Social inclusion, on the other hand, refers to the process of improving the terms for individuals and groups to participate in society through improved access to resources and services, opportunities as well as voice and respect for rights (United Nations Department of Economic and Social Affairs, 2016).

Achieving UHC in contexts of limited resources requires addressing inequities and fostering social inclusion through the design and implementation of health services packages that prioritise the most vulnerable, including rural populations.

South Africa is on the path to UHC to be funded through a National Health Insurance (NHI) scheme. The NHI Bill declares that priority should be given to groups that are in greatest need and experience greatest difficulty in obtaining care (National Department of Health, 2017, 2019). This will require prioritising vulnerable groups including the rural population which comprises 52% of the SA population and includes 75% of those living in poverty (Vergunst et al., 2016). In the country, the overall disease burden is higher in lower socio-economic groups, many of which reside in rural areas, largely due to entrenched structural inequalities and is exacerbated by poor access to services and greater social exclusion (van der Merwe et al., 2021). These healthcare access challenges are often greater in rural areas compared to urban areas (Samuel, 2021). While there is an overriding commitment to prioritise the most vulnerable there is at times a disconnect between what decision makers believe is most important to these groups and what their lived reality is, especially among the most vulnerable, whose voice is often neglected in the design of these policies (Wariri et al., 2017) (Wariri, 2017). The success of NHI in the context of limited resources will depend on appropriate, justifiable and acceptable decisions to ensure that those in greatest need are reached, simultaneously with public buy-in. One way to ensure identified interventions respond to the needs and values of the population and to increase the acceptance and success rate of these interventions is to give individuals, especially within vulnerable populations, greater control, and agency in designing health services packages. This too would strengthen social inclusion. Doing so would enable individuals to participate in the priority setting process where they are able to appreciate the implications of budget constraints and inevitable trade-offs. Globally there is increasing recognition that public values ought to be considered in priority setting for health (Abelson et al., 2013; Baltussen et al., 2016; Mitton et al., 2009) with different approaches proposed for eliciting these values and prioritising related interventions. These approaches focus either on individual level preferences that are aggregated, or on group level deliberation to reach consensus or a final solution (Baker et al., 2021). Both approaches are intended to overcome the challenge of competing perspectives in determining public preferences but also have their limitations. Aggregation fails to consider the reasons and justifications behind the preferences and makes no provision for shifting of priorities after considering others' views. Deliberation, while resulting in priorities that are based on informed and reasoned exchange and debate between individuals, may not always succeed at ensuring true representation and may overlook some important preferences especially if vulnerable groups are not adequately represented(Abelson et al., 2013; Baker et al., 2021). Deliberation also at times fails to consider dissenting views which may exist even after a group solution is reached, and may be overshadowed by stronger voices, or undermined by social pressure and confirmation biases (Oortwijn W et al, 2022; Oortwijn & Klein, 2019). Some have called for an approach that combines both these elements and aims to reach a broader public by considering individual level preferences as well as group decisions (Baker et al., 2021). Aggregated individual level priority setting may demonstrate alignment as well as differences with group choices, and individual characteristics like gender, level of education, age, income level and health status may be important to understand what drives some of these decisions. In some communities, especially within rural settings, a greater sense of the collective may exist, and the community good might be weighted more heavily even at the individual level (Lippman et al., 2018). This in turn may translate into individual level priorities that are very much aligned with community priorities. Where plurality exists, which is often inevitable with public engagement in priority setting, it may not always be possible to reconcile differences. However, legitimacy and acceptability of the decision-making process can be enhanced through ensuring transparency which would involve detailed reporting on the process including participant characteristics, as well as where conflicts emerged and how, or if they were resolved (Oortwijn W et al, 2022).

This paper aims to explore the outcome of a public engagement process for priority setting for health in terms of the choices and priorities of individuals as compared to group choices, as well as the socio-demographic characteristics that influenced decisions at the individual level. The paper considers how priorities might differ amongst individuals even within the same rural community, and the importance of transparency in this regard. The paper aims to provide insight into how marginalised voices, as well as broader publics, may be meaningfully incorporated in the priority setting agenda.

We used a modified priority setting tool called Choosing All Together (CHAT) that enables individuals and groups to make trade-offs to demonstrate the type of health services packages that may be acceptable to a rural population (Tugendhaft et al., 2021, 2022). The tool also can assist in determining the extent to which different characteristics may influence investment choices at the individual level. This is the first time such a tool has been implemented in a rural community in South Africa. While the tool predominantly caters for deliberative group level decision making, the individual level rounds provide an opportunity to understand individual level choices of this community. A separate qualitative analysis considered the outcome of the group level deliberative process (Tugendhaft, 2021). This paper presents the findings from the individual choices as compared to the group choices as well as the differences within the individual rounds, and some of the characteristics associated with these choices. Some previous analyses from the implementation of the CHAT tool have compared choices across rounds to demonstrate how individual level investments changed after participation in the group round and two analyses considered the sociodemographic characteristics associated with levels of investment for priorities (M.

Danis, Goold, et al., 2007; Evans-Lacko et al., 2012; Goold et al., 2018; Hurst et al., 2018). This paper adds to the body of work by considering the individual level health preferences of a rural community and demonstrates that even within this community where individual alignment with group priorities is potentially high, different preferences may exist among individuals with different sociodemographic characteristics.

Methods

Study site

The Agincourt Health and Socio-Demographic Surveillance System (HDSS) study area (https://www.agincourt.co.za/), platform of the MRC/Wits Rural Public Health and Health Transitions Research Unit since 1992, is located in Bushbuckridge sub-district in Mpumalanga Province. The area is typical of rural South Africa, characterised by poverty and underdevelopment as well as a strong traditional authority (Twine et al., 2016). It has a population of approximately 116,000 residing in 31 villages where life expectancy at birth is 68 for males and 74 for females (Kahn et al., 2012). Infant mortality rate is 39.1 and under 5 mortality rate is 10 per 1000 (Kabudula et al., 2021). The area is characterised by a quadruple burden of disease of HIV/AIDS and tuberculosis (TB); non-communicable diseases (NCDs); maternal, perinatal and nutritional conditions; and injuries. There are two health centres, six satellite clinics and three district hospitals within 20-60km from the villages. Sanitation systems are inadequate with 53% of the 20,000 households receiving pipe-borne water (Agincourt Health and Demographic Surveillance System, 2020). While access to electricity has increased, most still use a mix of energy sources. Tarred roads now link many of the villages but are maintained poorly and gravel roads are present within the villages. Every village has at least one primary school and most have a high school but the quality of education is poor (Twine, 2016 et al., 2016) with 54,9% of adults having passed matric. Unemployment rates are high and many households are dependent on government welfare grants (Agincourt Health and Demographic Surveillance System, 2020).

Materials

The CHAT (Choosing All Together) tool, originally developed by the US National Institutes for Health and Michigan State University, is a priority setting simulation exercise that allows participants to construct a health services package using limited resources (Goold et al., 2005) (Goold, 2005). During the simulation, a trained facilitator guides participants through different rounds (individual rounds and a group round) where they distribute a limited number of stickers on a board as they select from a range of options. The stickers, which represent the available budget, are only able to cover approximately 60% of the options on the board, the cost of which is represented by holes on the board.

The tool was modified for use in Bushbuckridge and described elsewhere (Tugendhaft et al., 2022). In brief, this modification process included an iterative participatory approach that relied on policy analysis and engagement with experts and community members to identify health topics and related interventions specific for the Bushbuckridge context, as well as a costing component. The outcome of the modification process was a context specific, bilingual CHAT board that included seven health topics/issues and related interventions within each topic/issue to select from as part of a health services package through the allocation of funds represented by stickers.

The CHAT SA board is included in appendix B and the health package options are summarised in table 10. The board is divided into pie slices with different icons for each slice. Each pie slice represents a health topic or issue, for example Child Health, and are further divided according to different categories of interventions represented by numbers.

Interventions were grouped together and categorized using the common classification of level of care for health interventions used in the South African health system: health promotion (1), prevention (2), diagnosis (screening) (2), treatment (3), rehabilitation(3), and palliative care (4) (National Department of Health, 2003; Department of Health, 2015). The access slice included five unique categories (numbered one to five on the board), which includes options like increasing the number of mobile clinics and improving attitudes of nurses. The total cost of the package of interventions is approximately R2 billion ($123 million) represented by 67 holes and each category of interventions per health topic/issue has a specific cost depicted by the sticker holes. Participants received 35 stickers which represented the funds they had available to allocate and that were able to cover 52% of the options on the board. This allocation was based on a starting point of 60% of stickers drawing on past CHAT exercises and was revised to allow for more meaningful rationing in the context of this specific board. The categories and specific interventions for each category were explained in detail in a user manual for each participant written in simple language and in the local language.

Table 10. Topics/issues, specific interventions and number of holes[*] of the CHAT board

Mother, newborn and reproductive health (MNRH)	**Number of holes**
1: Education and information	**1**
Two-month long media campaign on antenatal care (ANC)	
Two-month long media campaign targeted at adolescents	
Sex and reproductive education at schools	
Mobile messaging for pregnant women	
2: Prevention and Screening	**3**
Cervical cancer screening (three per lifetime)	
HPV vaccine at schools	
Contraceptive provision at schools	

Improve and provide more ANC- training of healthcare workers in basic ANC	
Exclusive breastfeeding – promotion and access to lactation specialists	
Complementary feeding- demonstrations	
3: Treatment	**2**
Expanded services for termination of pregnancy - make available in communities.	
Dedicated obstetric ambulances	
Maternity waiting homes	
Labour and delivery management	
emergency care for mothers and newborn	
Child health	
1: Education and information	**1**
media campaigns for immunisation and handwashing	
workshops on child health	
2: Prevention	**1**
Hand washing promotion in community	
Provision of food supplements for malnutrition & education	
Immunisations (at primary health care level)	
3: Treatment	**1**
Oral rehydration solution for diarrhoea	
Oral antibiotics : case management of pneumonia in children	
HIV/AIDS &TB	
1: Education and information	**1**
2 months long media campaign	
1 education workshop per year in every secondary school	
2: Prevention and Screening	**5**
Increase provision of condoms	
Youth friendly medical-male-circumcision services - include school friendly hours	

testing for HIV exposed babies	
HIV Counselling and Testing	
Making HIV Counselling and Testing youth friendly (training; extra hours)	
3: Treatment	**11**
ARVs & mobile messaging reminders for adherence	
Prevention of mother to child transmission of HIV (ARVs and breastfeeding choices)	
TB treatment	
Home based care	
STI treatment	
Youth Care Club	
Lifestyle diseases/ non-communicable diseases[§] (diabetes, hypertension, cancer)	
1: Education and information	**1**
Two-month long media campaign on lifestyle diseases	
Educational workshop on lifestyle diseases at community level	
2: Prevention and screening	**1**
School vegetable garden	
Increase screening and counselling in communities	
3: chronic medication	**17**
Diabetic medication	
hypertension medication	
Mobile messaging for adherence	
4. Treatment for complications and rehabilitation	**6**
Retinopathy	
Dialysis	
Amputations	

[§] Lifestyle diseases as a term was preferred by the community over non-communicable diseases (NCDs) during modification of the CHAT tool. Lifestyle diseases was retained in the CHAT board and user manual but NCDs is used throughout the paper to refer to these conditions.

Chemotherapy and radiation	
Rehab session for stroke patients	
5: Palliative care	**1**
Palliative care (in-patient)	
Palliative home based care	
Access	
1: Improve staff attitudes[**] (especially around family planning services for adolescents) and improve management and monitoring and evaluation in clinics	1
2: Make clinics operational for longer hours	4
3: Increase number of mobile clinics from 5 to 10	1
4: Chronic Medicines (ARVs, diabetes meds, hypertension meds) available at community health centres	2
5: Increase number of nurses in clinics and more pharmacists in clinics to dispense meds	1
Woman and Child abuse	
1: Education and information	**1**
Education/ life skills for children and adolescents, workshops on gender	
Media messaging	
Training and support workshops for families	
2: Management of rape and abuse	**1**
Care and support programmes, including counselling and comfort kit	
Training of nurses	
3: Treatment	**1**
Treatment of injuries at clinics	
Post-exposure prophylaxis 4 weeks	

[**] Referring specifically to nurse attitudes

Malaria	
1: Education and information	**1**
Annual education campaign	
2: prevention and screening	**1**
ITN & indoor residual spraying	
screening at clinics	
3: Treatment	**1**
antimalarial medication for uncomplicated cases	

*Holes represent cost of the intervention with one hole equivalent to approximately 1.5% of the total cost of the package

Sampling

Purposive sampling was used to ensure a range of age groups from different villages with different levels of infrastructure development and barriers to healthcare access, as well as a mix of men and women. The villages included three with clinics and three without; three with tarred roads and three with dirt roads. The sampling was conducted in this way to encourage diverse perspectives from this particular rural community.

Sixty-three individuals participated in seven group deliberations using CHAT, with 6-11 individuals in each group. There was a mix of women and men in each of the groups except for two which included one group with only older (55yrs) men and another group which included predominantly younger (23 years) women. There was another older group (52 years) with men and women, a younger group (25 years) with men and women and two mixed middle age (42years; 43 years) groups. Table 11 shows the group composition in terms of age and gender of the seven groups.

Table 11. Group composition in terms of gender and age

	G 1	**G 2**	**G 3**	**G 4**	**G 5**	**G 6**	**G 7**
Male	1	3	3	1	7	5	7

Female	5	5	8	10	4	4	0
Age range in years	37-62	30-67	30-55	20-28	20-42	40-66	48-67
Mean age in years	42	43	39	23	25	52	55

Study procedures

Prior to the CHAT exercise all participants in each group completed a short self-administered demographic questionnaire. The CHAT tool was used over three rounds. During round 1, after the facilitator explained the board and the accompanying user manual, participants individually allocated 35 stickers to the health issues and interventions that they perceived to be the highest priorities for their own family. Once this was complete, the group completed a board collectively (with 35 stickers) in terms of their priorities for the entire community of Bushbuckridge (round 2: group round). Scenario cards were used by the facilitator to assist participants in thinking through the implications of the decisions that they made. During this group round, guided by the facilitator, participants discussed the topics in depth and deliberated with one another to finally reach agreement (by majority vote) for the group allocations. Qualitative data was captured during the group rounds and analysed as part of a separate paper (Tugendhaft, 2021). During the final round (round 3), participants were again asked to complete the exercise individually (using 35 stickers) thinking about which priorities they believed were most important for their own family. At the end of the exercise the facilitator asked some brief feedback questions to the group before concluding. The entire exercise took half a day to complete.

Ethical approval for the study was obtained. An informed consent process was undertaken at the recruitment stage. Separate consent was obtained for audio recording. To ensure anonymity participants were given a participant number which was used throughout the study.

Statistical analysis

We used descriptive statistics to describe the study participants using the data from the questionnaire. The sticker allocations of all study participants were recorded at each stage of the study. From these the number of stickers allocated to each topic by the participants was calculated by adding up the number of stickers across interventions selected by the participant for the particular topic. For the group round, the value for each respondent was the value of their group. We calculated the median and interquartile range across study participants for the topic totals. The median referred to the median across all respondents for the particular round where n=63. To examine differences in sticker allocations, we performed Wilcoxon rank sum tests for differences across participant categories and sticker allocations in round 3. The participant categories were specified a priori based on the demographic data from the questionnaire. Results are reported as statistically significant if p <.05. All statistical analyses were conducted using STATA SE v 15.1.

Results

Participants

Table 12 shows the participants' characteristics. Participants (n=63) ranged in age between 20 and 69 years with a mean age of 39 years, and there were more women (57%) than men (43%). Twenty seven percent had a primary school level or no schooling and 73% had high school or above. Most households (57%) earned R3000 ($170) or below per month and were dependent on either solely government grants or a combination of grants and employment.

Table 12. Participant characteristics

Participant characteristics	n	%
Age		
20-45	39	62
46-69	24	38
Gender		
M	27	43%
W	36	57%
Education		
No school	7	11%
Primary school	10	16%
High school	41	65%
Tertiary	5	8%
Household Income		
R3000 and below	36	57%
R3001 - R5000	17	27%
> R5000	10	16%
Income source		
Government grants	19	30%
employment	11	17%
grants and employment	23	37%
Other	10	16%

Individual and group investments

Differences and similarities across rounds

Allocation of stickers by topic across all three rounds were very similar (Table 13).

Individuals in round 1 allocated a median of 9 stickers to NCDs, with more of a range, which increased to 17 in the group round and remained the same at 17 in the final individual round with a similar range. For HIV/AIDS & TB the median sticker allocation was 12 in all rounds but the range was higher in the individual rounds. Sticker allocations for other topics remained even more similar across rounds

Table 13. Number of stickers allocated by topic across rounds

	Round 1	Round 2	Round 3	*P-value*
	Median (IQR)	*Median (IQR)*	*Median (IQR)*	
MNRH3	3 (2 - 5)	2 (1 - 3)	3 (2 - 4)	0.041
Child health	2 (1 - 3)	1 (1 - 3)	2 (1 - 3)	0.88
HIV/AIDS & TB	12 (11 - 16)	12 (11 - 12)	12 (6 - 12)	0.32
NCDs	9 (6 - 17)	17 (8 - 17)	17 (7 - 17)	0.21
Access	4 (1 - 7)	5 (1 - 6)	4 (2 - 5)	0.63
Abuse	1.5 (1 - 2)	2 (1 - 2)	2 (1 - 2)	0.76
Malaria	2 (1 - 3)	2 (1 - 3)	2 (1 - 3)	0.54

Participant characteristics and patterns in investment levels

Among the participant characteristics - which included age, gender, education level, and income level - age was significantly associated with levels of investment in the different health issues during the final individual round. The difference across age groups is statistically significant for MNRH, Child health, Access and Malaria. Older age groups were more inclined to invest in these topics as well as for Abuse as indicated by a higher number of stickers allocated. For HIV/AIDS and NCDs the investment through the sticker values decreased with older age groups (table 5).

Individual income was statistically significantly associated with the investment in the health issues as indicated by the sticker allocations for NCDs and HIV/AIDS. Those earning R3000 and below invested less in NCDs and more in HIV/AIDS than those earning above R3000. Gender was not significantly associated in any of the allocations made and education was only statistically significant for Malaria (table 14).

Table 14. Participant characteristics and number of stickers allocated by topic, round 3

	Age >= 45	Age < 45		Men	Women		Income Above R3000	Income R3000 and below		High school and above	Primary school and below	
	Median	*Median*	*P-value*	*Median*	*Median*	*P-value*	*Median*	*Median*	*P-value*	*Median*	*Median*	*P-value*
	(IQR)	*(IQR)*		*(IQR)*	*(IQR)*		*(IQR)*	*(IQR)*		*(IQR)*	*(IQR)*	
MNRH	4.00	2.00	0.003	3	3	0,33	3.00	3.00	0.39	3.00	4.00	0.083
	(2.00, 5.00)	(1.00, 3.00)		(2 - 4)	(1 - 3.5)		(2.00, 3.00)	(1.50, 4.50)		(2.00, 3.00)	(2.00, 5.00)	
Child health	2.00	1.00	0.008	1	2	0,1	1.00	2.00	0.40	1.00	2.00	0.10
	(1.00, 3.00)	(1.00, 2.00)		(1 - 3)	(1 - 3)		(1.00, 2.00)	(1.00, 3.00)		(1.00, 3.00)	(1.00, 3.00)	
HIV/AIDS & TB	11.00	12.00	0.47	12	12	0,82	11.00	12.00	0.019	12.00	11.00	0.91

	(5.00, 12.00)	(11.00, 12.00)		(6 - 12)	(11 - 12)		(5.00, 12.00)	(8.00, 15.00)		(5.00, 12.00)	(5.00, 15.00)	
NCDs	13.00	17.00	0.38	17	17	0,72	17.00	13.00	0.033	17.00	9.00	0.45
	(7.00, 17.00)	(8.00, 17.00)		(7 - 17)	(8 - 17)		(17.00, 17.00)	(7.00, 17.00)		(8.00, 17.00)	(6.00, 18.00)	
Access	4.00	3.00	0.41	3	4	0,92	3.00	4.00	0.52	3.00	4.00	0.18
	(2.00, 5.00)	(2.00, 5.00)		(2 - 5)	(2 - 5)		(2.00, 5.00)	(2.00, 5.00)		(1.00, 5.00)	(3.00, 5.00)	
Abuse	2.00	2.00	0.75	2	2	0,67	2.00	1.50	0.90	2.00	2.00	0.89
	(1.00, 2.00)	(1.00, 2.00)		(1 - 2)	(1 - 2.5)		(1.00, 2.00)	(1.00, 2.00)		(1.00, 2.00)	(1.00, 2.00)	
Malaria	2.00	1.00	0.059	2	2	0,48	2.00	2.00	0.45	1.00	2.00	0.024
	(1.00, 3.00)	(1.00, 2.00)		(1 - 3)	(1 - 2.5)		(1.00, 3.00)	(1.00, 3.00)		(1.00, 2.00)	(2.00, 3.00)	

Discussion

The implementation of the CHAT SA tool in a rural community shows that individual interests were aligned in many ways with the societal ones as indicated by the similarities across the individual and group rounds with no statistically significant differences. Yet there were some differences within the individual rounds, which could be based on individual characteristics. In particular older age groups invested more in MNRH, Child Health, Access, Malaria while younger age groups invested more in NCDs and HIV/AIDS. Those with higher levels of education invested more in HIV/AIDS & TB and NCDs and those with lower incomes invested more in HIV/AIDS & TB and less in NCDs.

The similarities between the group and individual rounds could be explained by high levels of social integration at the community level (Lippman et al., 2018) which may be similar to other rural settings. Some previous CHAT analyses which compared individual and group rounds showed that individuals changed their preferences in the final round to be more aligned with the group choices (M. Danis, Lovett, et al., 2007) while others demonstrated that individuals reverted to their initial preferences even though these differed from the group (Hurst et al., 2018; Schindler et al., 2018). These studies were conducted in high income settings which differ considerably to low-income rural settings where community level social cohesion may not be as high. Our study adds to the body of work and demonstrates the importance of capturing the details of public engagement processes and transparently reporting on these details in order for the outcomes to be valuable.

Within the final individual rounds there are some differences in levels of investment among participants. Younger participants invested more in NCDs and HIV/AIDS & TB and less in MNRH, Child health, Access and Malaria as compared to older participants. This demonstrates that individuals were at times not only driven by self-interest and were considering broader, perhaps societal implications, of their choices. A further reason might

be because this community includes multigenerational households (Houle et al., 2023) and strong family ties which results in younger family members providing care for older family members, as well as grandmothers providing primary caregiver roles to grandchildren. Therefore, investments in interventions targeted at different age groups would be beneficial to the family unit (or appreciated by those even without a direct benefit).
In terms of Access, older individuals may have invested more in this area due to actual challenges that are experienced such as access to chronic medications as well as travelling long distances to hospitals, which can be even more challenging for the elderly. This indicates that priorities of individuals within vulnerable groups do differ and speaks to the need to ensure diverse age groups are included in priority setting processes.

The CHAT tool is unique in that it allows for both individual level and group level decision-making. Although choices were similar across rounds in this community, other CHAT exercises, mostly in higher income settings, have demonstrated more divergence. At times, group deliberations have not only impacted the group choices but also the final individual choices (M. Danis, Lovett, et al., 2007; Evans-Lacko et al., 2012). This demonstrates that individual level and group level processes can influence one another and public engagement in priority setting may be more meaningful as part of an iterative process at various stages of decision-making.

Our results support other viewpoints that if public engagement in priority setting is viewed as important, the challenges of reconciling plurality will need to be overcome, even within populations with strong levels of social cohesion and alignment (Baker et al., 2021). Group deliberative approaches help to reach consensus and reconcile some of the differences, but additional individual voices may also need to be considered alongside group processes, especially among the most vulnerable. This speaks to the need to ensure representation of the different “publics” in priority setting for health, with strong consideration of the heterogeneity of the South African population, and especially vulnerable populations.

Deliberative methods, while successful at capturing reasons behind choices, and developing a deeper understanding of the values of communities, may overlook some important priorities and may not effectively reach enough of the public. Consideration should be given to implementing these tools alongside other individual level engagement mechanisms. In doing so, some of the standard approaches of individual level preference capturing may need to be modified to ensure voices of the most vulnerable, including rural populations, are captured. National level surveys, for example often rely on the use of devices that are not always appropriate for rural communities who are difficult to reach. These individual level engagement mechanisms would also benefit from depicting choices within a constrained budget otherwise it proves difficult to translate public priorities into policymaking for health (Hurst, 2018). The outcome of these broader engagements would not be sufficient in determining a final decision but could be useful in guiding decision makers as one component in a broader priority setting process that also considers wider ethical considerations and economic evidence.

Another way to respond to plurality, especially in the context of UHC is to consider multiple health services package options. Others have demonstrated that individuals can live within constraints but in different ways and may support the view for a more individualized approach to UHC where different preferences are taken into account (M. M. Danis et al., 2002). Our analysis shows that age may be one criterion that should be considered in the design of health services packages and different packages may be appropriate for different age groups. More broadly, specific packages for vulnerable populations, including rural groups, might be valuable. Equity considerations are already promoted in priority setting processes and the voice of vulnerable could be included for this to be more impactful. In South Africa, national level priority setting for health policies could incorporate vulnerable voices but at provincial and local level where service delivery decisions are being made rural voices should influence these decisions to ensure they are more appropriate for and responsive to different local settings. Further refining these packages according to additional characteristics like age could be beneficial.

Finally, while plurality may not always be reconcilable transparently capturing and reporting on public engagement processes can contribute to a deeper understanding of community priorities and competing viewpoints, as well as greater acceptance of final decisions.

This paper demonstrates one approach for potentially improving social inclusion and shows how vulnerable individuals and groups can have their voice included in decision making for healthcare. Incorporating this voice would in itself improve social cohesion, and if the outcome of such exercises were translated into policy and service level decisions then barriers to accessing healthcare would be addressed thereby further promoting social inclusion. Social inclusion, however, is multi-faceted and can only be fully addressed by paying attention to the broader political, economic and social environment. This paper is potentially one step in the right direction providing lessons on how social inclusion can be improved for vulnerable communities through greater agency and control in health service package design, and in turn can impact illness and access vulnerability.

Limitations

The demographic information we captured was limited and our results could have been strengthened if it had been more extensive. Health status as well as household composition would have been especially valuable as this could have potentially added to our understanding of some of the investment decisions.

Our sample size was small and it is possible that there was insufficient power to detect small differences between rounds of the deliberative processes. Our sample was not large enough to run multivariable regression models and as a result we were not able to adjust the results for other factors. For example, individuals who were older AND female may have made different choices to older males. In addition, the sample was purposive to ensure representation from different villages in the study site, different age groups and both male and female participants. This could have resulted in selection bias.

A further limitation is that the data points in round 3 are not independent and we did not adjust for correlated data. However, the comparison across rounds demonstrated that the difference between round 1, where the data points are independent, and round 3 was not statistically significant so adjusting for intergroup comparison may not have been necessary.

Group dynamics was not considered in terms of impact on individual level decisions, this should be explored in the future

Conclusion

Successfully Achieving NHI in South Africa, and making progress towards the 2030 SDG targets, will rely on reaching the most vulnerable by ensuring policies and related interventions are responsive and appropriate and address social exclusion. Public engagement provides an opportunity to ensure these voices are included in the decision-making processes. Group level and individual level engagement approaches have strengths and limitations, and both may be necessary to ensure accurate capturing of priorities, and underlying values of marginalised groups. The CHAT process demonstrates that rural groups and individuals can grapple with the idea of limited resources and difficult allocative decisions and provides an example of how excluded voices may be meaningfully incorporated in the priority setting agenda. The study shows that even in communities with high levels of social integration, individual level preferences can differ, and these preferences are shaped by different characteristics. This CHAT implementation demonstrates meaningful outcomes, which could be useful to policymakers. However, to bolster its utility further, research should focus on extending its implementation with more individuals and groups, within the same rural area as well as beyond, and within urban areas. This could be conducted alongside other aggregation methods. In doing so, a deeper understanding of social values as well as associations between individual preferences and characteristics would emerge which could inform health service package design, especially if policymaker engagement is included from the outset. In addition, efforts around the institutionalisation of priority setting in South Africa would benefit from the equal input of experts in methods of public engagement alongside other technical experts in priority setting. This could lead to more effective decision making which in turn could improve health outcomes.

Chapter 7

7 Discussion

This thesis aimed to investigate the feasibility and practicality of including the public in resource allocation and priority setting for health in a rural setting in South Africa. To address this, the research focused on modifying a specific public deliberation tool and then implementing the tool in a rural context to explore the process and outcome of applying this approach. Specific objectives for the research were to a) Identify and cost priority health topics and interventions in order to modify the CHAT tool for a South African rural community context; b) Explore the group deliberation process and outcomes using CHAT to identify what issues were prioritised by community members, the reasons for these selections and how negotiations and engagements with trade-offs took place within the groups and; c) Explore the outcome of the group deliberative exercise as compared to the individual level exercise for priority setting for health and characteristics that influence decisions at the individual level. The purpose of this chapter is to highlight the overarching findings of the thesis and to discuss what has been learned overall. This links with the concluding chapter which considers implications for research, policy, and practice in the public engagement space.

7.1 Summary of thesis findings and how objectives were achieved

Chapter 4, modification of a public engagement tool for priority setting for a rural South African context, focused on documenting the participatory iterative method for modifying the CHAT tool for the rural context and the outcome of this modification process. I demonstrate the various steps for modifying the CHAT tool in a participatory way which includes review of policy documents and engagement with decision makers at local and national levels as well as with community members, and a modified Delphi method. In addition, the costing component involved review of the literature, as well as a high degree of expert consultation in a context of limited costing data availability. The outcome of this approach was that health topics/issues and related interventions were identified for the CHAT board that reflect priorities of both decision makers and, importantly, community members which in turn would impact the acceptability and appropriateness of the tool. The work shows that community members and policymakers are not always aligned in terms of health challenges and solutions to these challenges, and that for health services packages to respond to the needs of those on the ground, inclusion of the public, especially marginalised groups, during the agenda setting stage, as well as in the design of engagement methods would be beneficial. Context specific tools could be helpful in the South African context in facilitating meaningful participation, as conceived by the Constitution, and entrenched in policy documents, and should be developed as part of priority setting institutions to be readily available for use. The modification of CHAT serves as an example of how to apply participatory engagement principles to the development of context specific engagement tools and highlights some specific priority health areas and related interventions to be further explored for inclusion in a health services package (Tugendhaft et al., 2022).

Chapters 5 and chapter 6 focus on the implementation of the CHAT tool in rural Bushbuckridge. Chapter 5 considers the group level deliberative exercise of CHAT and explores the outcome of CHAT in terms of what was prioritised by the groups and the reasons for these decisions. The chapter also analyses the process in terms of how the participants grappled with trade-offs and the negotiations that took place in the context of limited resources. In terms of the outcome, CHAT enabled the groups to prioritise interventions that they deemed most important in a context of scarce resources. Those that were highest priority included treatment for HIV/AIDS and TB; provision of immunisations and food supplementation for children; and increasing the number of mobile clinics. These were followed by interventions that focused on prevention and treatment for malaria; chronic medication for NCDs; making clinics operational for longer hours; education for reproductive health as well as for HIV/AIDS and TB and violence against women and children (this consisted of media campaigns, community-based family workshops and mobile messaging)

(Tugendhaft et al., 2021). In this context of constrained resources as per the CHAT exercise, the interventions that were not prioritised or received low priority included prevention interventions for HIV/AIDS and TB and for reproductive health; education interventions for child health and NCDs; making chronic medication available at community centres and increasing the number of pharmacists and nurses. While it was clear that most of the interventions on the CHAT board were important to the group, the limited budget available in the form of stickers resulted in a process where participants grappled with difficult allocative decisions and considered trade-offs (Tugendhaft et al., 2021). Often there was ongoing back and forth during the discussions where participants weighed up the pros and cons of investing in one intervention versus another. Much of the group discussions were dominated by barriers to accessing treatment hence there was a focus on interventions that addressed treatment and improved access. It was also clear from most of the groups that community-level interventions for improving information and awareness would be more beneficial than existing -school-based programmes, or national media campaigns. The implementation of CHAT demonstrated that the exercise was able to elicit outcomes in terms of priority interventions and associated justifications and values driving these priorities, and that the process itself encouraged deliberation and engagement with trade-offs to reach consensus in a context of scarce resources (Tugendhaft et al., 2021).

Chapter 6 considers the outcome of the CHAT exercise in terms of the choices of the individual rounds as compared to the group rounds as well as the socio-demographic characteristics that influenced decisions at the individual level. Interestingly in this case, younger participants (20-45 years) prioritised HIV/AIDS and NCDs over reproductive health, child health and access compared to older participants (46-69 years). The chapter demonstrates that even when there is strong alignment between individual and group level priorities it may be important to consider the individual choices alongside group outcomes, and the characteristics that influence these decisions. This can contribute to ensuring more of the public is included in the priority setting agenda but also can ensure dissenting views are considered and reported on, ensuring greater transparency around public engagement processes.

The conceptual framework developed in chapter 2 (page 36) is revisited here and provides a mechanism for considering the overarching themes that have emerged from the thesis The evidence for these themes is drawn from the findings of the three papers presented in the thesis in Chapters 4, 5, and 6 and supported by the literature. Some additional quotations are provided from the data that were not used in the results chapters.

7.2 Moving from tick box to meaningful engagement – a cyclical dynamic collaborative approach

The literature demonstrates that there are different conceptions of public engagement and different approaches and methodologies to enable this. My work was concerned with meaningful engagement in priority setting for health which relies on active involvement by the public in decision making activities for the development of health polices and services (Florin & Dixon, 2004). This is part of a broader movement away from professional dominance to democratic participatory processes and focuses on decentralised decision making to better reflect local preferences. My adapted conceptual framework for meaningful public engagement in priority setting for health demonstrates a cyclical dynamic and collaborative approach which incorporates different factors that all interrelate and impact one another. These factors include the different levels of decision making; the different perspectives that interact during decision making; the methods that enable public engagement (and the evaluation that further impacts these methods); as well as the broader environment (political, economic, and social space). These different factors are unpacked below in relation to my PhD.

7.2.1 Deliberative methods of engagement

Some public deliberation methods may be more appropriate than others depending on the goal of engagement, and this needs to be considered when selecting the method (Danis, 2019). Because my work was concerned with meaningful engagement in decision making, deliberative engagement methods were deemed more useful and appropriate to facilitate this. In this context, meaningful implies that the engagement goes beyond consultation or tokenism to foster empowerment through deliberation among groups of individuals and to find collective solutions to social problems. The outcome of which should impact decision making (Blacksher, 2013; Baker, 2021; Mitton, 2009). The CHAT tool specifically, was most appropriate as it was designed in accordance with democratic deliberation principles (Goold, 2005) and includes the essential components laid out by Blacksher (2012) for successful meaningful public deliberation including provision of factual and balanced information, diverse perspectives, and a setting where moral claims can be voiced and challenged. The exercise provided participants with *information* in the form of description of interventions, costs of interventions and implications of the interventions; it ensured a range of age groups from different villages with different levels of infrastructure development, and a mix of men and women to ensure *diverse perspectives* from this particular rural community; and it enabled an environment where *values and opinions were voiced and challenged* (Blacksher, 2012). This was evident from the group discussions in Chapter 5 and further supported by the following quotation:

"I also support her 30% on this one as well. My 70%...well I am not saying that what she has said is wrong, but we also have to look at our money and there are many areas that are important and they are not important to us; but to the whole of Bushbuckridge. so when we look at our budget, I think that we should choose one thing under child health so that we can be able to cover the areas that we have not done anything on them." (G2, P4)

The fourth component for meaningful engagement in priority setting for health which is included in my conceptual framework in chapter two - that being the consideration of priorities within a constrained budget- was clear through the CHAT exercise. Although some public deliberation conceptions seem to be implicit about the idea of rationing, many methods of public deliberation do not include this component as explicitly as CHAT does. While deliberative approaches can be successful at eliciting social values and considering societal perspective, communities will likely prioritise differently when the choices are expressed in the context of constrained resources (Baker, 2020). As one of the participants expressed:

"That is what I was saying that it is just that we don't have enough money, we would budget for every health service area that is on this CHAT board (if we had more money)." (G3, P4)

Therefore, it is important to consider priorities of communities not simply through deliberative approaches to supplement priority setting, but rather to have an approach that enables communities to grapple with resource allocation decisions and in this way to improve the chances of being included in the priority setting process. This work provides an example of how a community was able to grapple with these types of resource allocation decisions, how they considered different perspectives and societal implications and were able to set priorities together, as was evident from chapter 5 (Tugendhaft et al., 2021).

As part of an iterative, dynamic, and participatory approach to public engagement there is benefit in the inclusion of the public in shaping these deliberative methods of engagement (Tritter & McCallum, 2006). This is linked to the importance of the public in identifying challenges as opposed to only solutions (Tritter & McCallum, 2006), and being included in setting the agenda for healthcare coverage decisions. This presumably should occur alongside expert input in the design and development of these methods. In addition, ensuring the deliberative method is context specific ultimately improves the success rate of implementation and the acceptability of these methods. My work partially addressed both these elements through the participatory approach and the inclusion of Bushbuckridge community in the modification of CHAT. The iterative participatory approach which involved policy review and engagement with experts and community members contributed to identifying contextual issues and, specifically, enabled the identification of issues and challenges faced by the community as well as the proposed solutions, the outcome of which was used for the modification of the tool. The work not only produced, for the first time in South Africa, a context specific deliberative tool but also provides detail of a participatory modification approach. The methods used in this modification are replicable and can be applied to further adaptations of CHAT or other engagement tools. The cyclical framework demonstrates that public engagement methods may change overtime, and that multiple methods might be required to capture various perspectives at different levels. Lessons from this work can be applied in the modification and implementation of other methods.

7.2.2 Evaluation of deliberative methods of engagement

While CHAT was intentionally selected as the specific method for this work, it is important to consider some of the shortcomings in relation to CHAT and deliberative engagement approaches more generally. This can be fully appreciated only through a consideration of the way in which these approaches are evaluated.

A normative perspective may consider CHAT and other engagement approaches valuable in and of themselves (Weale, 2016), however, moving beyond this the literature highlights the lack of established evaluation criteria for public engagement exercises (Abelson et al., 2013). While the overriding goal of a particular engagement can and should guide the evaluation (Danis, 2019). meaningful evaluation requires deeper analyses to assess the process and outcomes of public engagement initiatives. There are some guiding criteria for evaluation, which are interlinked with components for successful engagement as laid out by Blacksher (2012) and addressed above. In terms of the process of public engagement exercises, some of the criteria which are proposed include that the process be legitimate, reasonable, transparent, responsive, equitable and fair; that it ensures mutual respect; and provides time and space to challenge the information provided (Abelson, 2003; Danis 2019, Thurston, 2004; Goold, 2019). Regarding the outcomes, the guiding criteria include impact on decision making; satisfaction of participants and a more informed public; degree to which consensus was reached; and identification of priorities and values (Abelson, 2003; Danis 2019; Thurston,2004; Goold, 2019). There is, however, limited evidence in this regard beyond the priorities that are identified as part of engagement exercises.

Some studies have been conducted that consider how the process influenced participants views, and if participants were satisfied with the process (Danis et al., 2019; Reckers-Droog et al., 2020). As I discuss above, and presented in the results in chapter 5, the CHAT exercise encouraged debate and challenging of views, and participants seemed mostly satisfied with the final priorities in the groups as none expressed desire to change any sticker allocations when asked at the end of the exercise by the facilitator. In addition, chapter 6 demonstrates that individual priorities in the final round were very much aligned with the group choices. The exercise also resulted in the identification of priorities and values driving these priorities as presented in chapter 5. Thus, my work does align with some of the process and outcome considerations. In addition to this, my work included some brief questions at the end of the group deliberations which pointed to level of appreciation of the participants, as well as capacity development in terms of greater understanding of priority setting and resource constraints. As expressed by the participants:

“It has been a good exercise and we wish we can come back again for another exercise. We had a great time here and it was a mind opening exercise for us as youth. It was a platform for us to voice out what we want for our communities and say the problems that have been bothering us for a long time.” (G4, p6)

“It was a great exercise and we have enjoyed it a lot because we have even learnt about the problems that our communities are facing here in Bushbuckridge.” (G 6, P1)

“We have learnt a lot and we have come to an understanding that there are some things that the government cannot do for us because there are many things that the government has to consider before they can provide.” (G7, P3)

“I have learnt that there are certain things that the government cannot provide for us at the same time because they are looking at what is important before they can give to the

community. So now I understand that the government is doing things by looking at the money that it has at that time." (G5, p4)

However, participant satisfaction and knowledge development was not considered in depth. Partly due to the CHAT exercise taking a long time to complete (approximately 5 hours) which resulted in follow up questions being brief. In addition, there were follow up interviews planned with two participants per group but there were challenges with this. Most of the participants were not available or could not contribute sufficiently to the follow up. This element should be further explored, especially among individuals who prioritised differently in the final round compared to the group rounds as they may have useful reflections on the CHAT exercise.

Impact on decision making- the complexity of policymaking

If one of the important goals of public engagement is indeed to influence policymaking, then it may be necessary to consider what elements the deliberative method should include that could increase chances of success in this regard. While the benefit of the inclusion of resource constraints in a public deliberation exercise has been addressed, this may not be sufficient to impact decision making. The literature demonstrates that priority setting should take into account value for money considerations which are often expressed through cost effectiveness analyses (Baltussen et al., 2016; Chalkidou et al., 2016). This goes beyond costs of interventions as is captured in the CHAT tool. The question then is how this type of data could be incorporated in CHAT (or other public deliberation methods). This could enable participants to consider not only the costs of the options on the board and the benefit and consequences of the options as described in the user manual and the health event cards (alongside the value judgements they engage with through the exercise) but also measurements of cost effectiveness such as DALYS (disability adjusted life years) or QALYS (quality adjusted life years) used in traditional priority setting approaches. A starting point might be that instead of presenting in-depth technical information, the user manual could include whether the intervention is cost effective or not, with a section of the discussion at the beginning of the exercise dedicated to explanation of cost effectiveness. Another option might be to only include options on the board that are cost effective. My CHAT work, as well as others ((Iddo. Dror, 2007; Goold et al., 2018; Hurst et al., 2018) demonstrates that the general public, and especially rural groups, can appreciate resource allocation dilemmas and engage with information around the costs and benefits of interventions, therefore it should be possible to extend this to incorporate cost effectiveness information in a manner that is accessible to the public. However, the limitation of cost effectiveness data, especially in LMICs may make this prohibitive. Extending this point, notwithstanding the limited availability of cost effectiveness data, it might also be worthwhile considering what a public engagement tool would look like if it included multiple considerations beyond cost effectiveness and provision of information that could demonstrate the impact of the options on the board in terms of equity and other criteria used in extended cost effectiveness analyses or through the application of ethical frameworks for priority setting. In my implementation of CHAT participants may have prioritised differently if this information were provided, in the same way that the resource constraint considerations influenced their choices. CHAT may have the potential for including these multiple considerations or may need to be supplemented with other engagement methods to achieve this.

Even if a public engagement approach/es could include these elements, it might still prove difficult to impact priority setting, and the evidence supporting this impact is limited (Danis, 2019). As many authors point out, the political context where policy decisions are made is complex and has a significant influence on the outcome of public engagement (Danis,2019; Thurston, 2004). At most then, public engagement can be one of several factors impacting decision-making. Furthermore, even if public engagement does have an impact on decisions there are challenges in terms of demonstrating a causal relationship (Danis, 2019). My work demonstrates that a rural community can engage with and appreciate resource allocation decisions and set priorities for health as a group. The CHAT tool was designed to simulate priority setting and the outcome of my work is potentially a first step to demonstrate how the public can be included in this process. However, to date it did not have any impact on actual priority setting for health.

Many of the limitations of public engagement noted in the literature regarding actual decision-making could potentially be overcome if public engagement were entrenched within the priority setting process where the public and decision makers were engaging on an ongoing basis as part of an iterative approach (as demonstrated in my conceptual framework). This would require moving towards more of an institutionalised systematic public engagement in priority setting process where meaningful public engagement is a core feature of all priority setting exercises. This, however, might include different methods of engagement depending on the type and level of decisions being made. In addition, if there were greater transparency around priority setting where decision makers report on how decisions are made and what considerations are taken into account, then the causal relationship between public engagement and priority setting might be better understood.

Beyond the goals of engagement, and linked to the criteria mentioned above, Danis (2019) points out that access and equity considerations are important when selecting and evaluating a method. This refers to barriers of participation and time and capacity that is available to participants. This is consistent with my literature review which considers the structural barriers to meaningful and equitable public engagement in LMICs including physical access, poverty, social exclusion, and the low social status of women in many settings (Alderman, 2013, Kapariri, Arthur). These elements are captured in the broader environment component of my conceptual framework. Methods that address these challenges would ensure fairer and more balanced participation, ultimately impacting the process. In addition, follow up is often important for public engagement and should be considered in selection of the methods (Danis, 2018). My work aimed to address some of these barriers by focusing on a rural population and recruiting participants from a mix of villages with different levels of infrastructure as well as ensuring women were represented. Because the research was embedded within an established research centre the fieldworkers were experienced beyond the CHAT training that they underwent and were able to recruit relatively effectively. However, some participants did drop out before implementation. In terms of implementation, a study vehicle was used to collect many of the participants and the exercise took place at a central location at the research centre. Because CHAT is already a time intensive exercise, any additional lateness can have negative effects. On some days bad weather made transportation difficult and delayed others who travelled by foot, resulting in a delay to the start of the CHAT exercises. This meant that, some of the reflections at the end had to be done rapidly and some of the other sections might have been rushed. In addition, not all participants were literate and so could not read the user manual. I made provision for this by ensuring there were extra fieldworkers to assist with reading the user manual. However, this potentially undermined the level of engagement of some of the participants, as they would have required additional time to use and apply the information to the discussions. Furthermore, some participants were more vocal than others and this could have been due in part to not feeling as confident with the information in the user manual. Follow up interviews specifically with those who were illiterate might have been valuable. Another question which emerges is whether CHAT should include a different way of depicting the options on the board – for example moving from a written user manual The use of graphics and perhaps posters when it is implemented with illiterate communities. Power dynamics were also not explored in the work but could have been at play and stronger voices may have led to group think. Again, individual follow up interviews would be useful to elicit some of this and is in line with the recommendations made by Danis (2019) that where follow up is important the right type of method to enable this must be considered. In addition, if public engagement should be an iterative and ongoing process then there might be benefit in the inclusion of other methods alongside CHAT to enable this, especially where communities face time constraints and other barriers to participation.

Cost effectiveness of public deliberation methods

Another evaluation criteria which is given very little consideration in the literature is cost effectiveness of deliberative engagement methods (Abelson, 2003). There is little documentation of the detail and costs of deliberation engagement methods and evidence of value for money of these approaches. This is linked to the lack of established evaluation criteria as discussed above. Research is also lacking that compares different deliberative approaches or compares the outcome of deliberative approach with non-deliberative approaches (Abelson, 2003).

Capturing true efficacy of public deliberation methods as well as costs and opportunity costs is challenging. In my case the modification and implementation of CHAT was resource and time intensive. The participatory iterative approach required several engagements, and the costing exercise (as described in chapter 4) relied on several assumptions but also consultations with experts which took time. The materials including the board and health event cards were developed, designed, and translated through various iterations. The training of the fieldworkers as well as implementation (also described in chapter 5) required further resources including time, materials, travel, accommodation, and food. While the results chapters do not document the actual costs of modification and implementation, the detail of the process is captured (unlike many other public deliberation modification processes). This can serve as starting point to capturing some of the costs associated with a public deliberation exercise but can only be fully assessed in terms of value for money if outcomes are evaluated deeply.

A further point to consider is that CHAT may not always require such an iterative participatory approach for modification. My conceptual framework speaks to the importance of including the public in the design (or modification) of engagement methods and the value of a context specific tool. However, there may be instances where issues and solutions have already been addressed through other research initiatives, especially through approaches like participatory action research, and CHAT could provide the next step in terms of translating these solutions into costed interventions and then prioritizing these costed interventions through implementation of CHAT. In this way, modification costs could be averted but implementation costs would still need to be considered.

7.2.3 Perspectives

Public perspectives: user/individual and public policy/community

When engaging the public in priority setting there are different perspectives that need to be considered. These perspectives overlap and influence one another. Demaio (1993) classifies these as user and public policy perspectives and are captured in my conceptual framework. The former is focused on concentrated health interests of oneself, family or, in this case, the village and the latter is concerned with the broader public or community (societal interests), in this case Bushbuckridge. The literature deals with individual level preferences which are often captured through aggregation and social values which are more appropriately captured through deliberative approaches (Baker, 2021). However, deliberative engagement methods can and do interact with both individual and societal interests. The CHAT tool is an example of an approach that is able to capture both of these perspectives. As described by Goold:

The exercise seeks to provide an opportunity for "advancing both individual and collective understanding"(Gutmann and Thompson 1997: 40) as individuals learn about the realities of limited resources and the consequences of the trade-offs they make when allocating those resources. Attempts to balance equity and efficiency are facilitated as participants simultaneously weigh desired... services against the realities of resource constraints…CHAT was designed to promote communal values while preserving individual autonomy (Fleck 1992, 1994); both individual and group preferences and values are solicited. (Goold, 2005)

The CHAT implementation demonstrated that both these perspectives were at play, as was presented in chapters 5 and 6, and further expressed by the following:

"We have learnt how to choose the things that are more important for us as individuals and what is important for our community of Bushbuckridge" (G2, P7)

These two perspectives do not operate independently of one another but are interlinked and influenced by the broader environment. From the implementation of CHAT, it was clear that through the deliberation individuals came to appreciate the implications of some of the interventions on the community and chose, in some cases, to invest in areas that did not necessarily provide a direct benefit to themselves as healthcare users, or they had not considered important at the start of the exercise.

"I don't have a reason why I did not choose it but after listening to that story, I would choose education so that as a mother I would be able to learn what to do to prevent my child from all those diseases, and I would also learn the importance of immunisation" (G4, P1)

Chapter 6 demonstrates that there was strong alignment between the final individual and group rounds but also that preferences among individuals did differ and may have been influenced by characteristics like age. This concept goes further and could be developed by considering the way in which social interactions, and the broader environment (social, political, economic) impact individual and community perspectives in rationing decisions. In my work, one of the areas that was prioritised for inclusion in the CHAT board during the modification phase was malaria and related interventions. The outcome of the implementation phase demonstrated that participants were greatly concerned with this topic and majority of the groups chose treatment and prevention for malaria. The area is impacted by seasonal malaria and the groups' choice was likely influenced by a malaria outbreak at the time of data collection. This demonstrates that the context and broader environment is important in understanding community and individual priorities. It also highlights that priorities can and do change over time, shaped by personal circumstances, and the broader environment, and speaks to the need to ensure public engagement initiatives are ongoing and not simply once off, as was the case with this work. The cost requirements of doing so, as outlined above, would need be considered.

An additional component which is important in relation to public perspectives within public engagement exercises is transparency. This should include transparency around the outcomes of the exercise, including dissenting views, as well as ensuring that demographic characteristics and broader contextual factors are reported on alongside the outcomes. This would develop our understanding of engagement processes and their outcomes and would strengthen legitimacy of the process.

Decision maker perspectives

Conceptions of public engagement approaches focus predominantly on public perspectives, be it as patients, individual users, or members of broader communities. While this is sensible my conceptual framework aims to assist in moving towards a collaborative shared decision making one (Tritter & McCallum, 2006). In doing so, I propose that any framework/model/approach to public engagement in priority setting include decision makers' perspectives as a factor within the framework, not simply outside (or usually above) the framework. This would facilitate moving beyond a system where decision-makers set the agenda and seek public input as tick box exercises at later stages often to satisfy expressed commitments or to justify pre-determined priorities. True engagement should account for the interaction between the perspectives of decision makers and the public and consider the influence both may have on the other. In this way, a feedback loop would be created. My work takes the first step in trying to achieve this but does not fully succeed in completing the cycle. The engagement with policymakers and with community members in the modification of CHAT, as well as the iterative approach and triangulation of data was a method that merged views from the bottom and from the top and resulted in a context specific engagement tool that included community priorities. The modification phase (chapter 4) and the implementation phase (chapter 5) demonstrated that there was some alignment but also strong divergence, especially between national policy makers and community. It was clear specifically from the modification phase that the way in which problems and solutions were framed differed, this was especially relevant regarding access issues, as presented in chapter 4. This was also evident when comparing some of the outcomes of the CHAT implementation to existing national policy initiatives.

To bring these perspectives together, and understand the impact one has on the other, more is needed during modification, implementation and post implementation of deliberative engagement tools. One option might be to bring both decision makers and community members together in the same room when implementing these tools. This would require buy- in from decision makers and willingness to engage from community members. Power dynamics would also need to be considered and addressed. Alternatively, there could be a feedback loop where the outcomes are presented back to decision makers, who provide a response which is then communicated back to the community and a final round is concluded. There are clear limitations in this, not least due to time constraints and so additional methods, like the Delphi method, might be useful for supplementing deliberative approaches whereby different perspectives need to be reconciled. Others have also proposed combining deliberative and non-deliberative methods in order to maximise their contributions and overcome their limitations. For example, Whitty and colleagues propose joining citizen juries and DCEs (Schoon & Chi, 2022; Whitty et al., 2014), although this can be even more costly and time consuming. The combination of deliberative and no deliberative approaches could also assist in reaching a larger public. Importantly, if public engagement were institutionalised within the priority setting process, then bringing the different perspectives together, and ensuring an iterative approach would likely be easier to achieve.

In addition, evaluation of these methods (as addressed above) in terms of impact is important to bring the different perspective together. Without evidence of impact, decision makers may not be incentivised to engage with the public, and the public may not remain engaged (Tritter & McCallum, 2006).

7.2.4 Decision making levels: Macro and Meso

The literature demonstrates that public engagement for priority setting for health can and should takes place at different levels including national, provincial, and local. It is at these different levels that the perspectives described above interact. Drawing on De Maio (1993) I identified two main levels for the purpose of this work. The macro level policy decisions and allocation of resources at national level and the meso provincial/local level which is concerned with service delivery decisions (including what services are delivered, where and by whom) for the specific districts. The modification phase of CHAT as well as the final modified tool included components of both macro and meso level decisions. The modification included review of macro level national policies to identify priority areas at national level and then to refine this for the local context by reviewing local level policies and engaging with local level decision makers and community members (ref paper 1). While the final options on the CHAT board were costed for the local context and predominantly focused on local and community level interventions, many are linked to broader macro level policies. For example, one of the components of prevention under reproductive health in the CHAT exercise is the provision of HPV vaccine at schools, however, this is directly linked to national policies for school health that would be required to support this intervention. As DeMaio points out, these levels are not independent but influence one another- “decisions in the service delivery domain must be taken within a broader provincial and/or national health policy context” (DeMaio, 1993). In the same way, decisions at the national level must consider the local context and how policies and budget allocations will translate into service delivery interventions on the ground. Public engagement in priority setting then should allow for the interaction of the different levels and the different perspectives at these levels. This can facilitate a decision-making approach that is more collaborative and less adversarial. The CHAT tool could potentially be useful at the national level when policy decisions are being made and when budgets are being allocated, and in the future as part of the priority setting institutions that evolve in South Africa. At provincial/local level, building on the “”Batho Pele” (people first) principle mentioned in the introduction (Department of Public Service and Administration, 1997), decision makers could benefit from the use of tools like CHAT to include the public in resource allocation and service delivery decisions. Through the implementation of these tools the values of the National health Act and the White Paper on local government could be upheld and municipalities could be supported in including active participation by citizens to ensure the policies reflect community preferences (Government of the Republic of South Africa, 1998; South African Government, 2003).

Specifically, tools like CHAT could potentially elevate the roles of community health committees from that of pseudo community health workers to active decision makers if indeed these committees are supposed to ensure community participation in the priority setting process for local clinics. While many limitations of the CHCs have been identified (Haricharan 2021; Padarath and Friedman, 2008.), some of these may be overcome through the inclusion of an approach that enables these committees to grapple with resource allocation decisions in a meaningful way and CHAT provides an example of how to potentially achieve this.

There are also other important decision-making spaces that are worth considering. In the context of this work the decision-making space referred to government level decision-making at national and local/provincial level. The community health committee were considered in the literature review as an extension of local level decision making. However, decision making for health interventions is not always about government decision makers. Especially in LMICs, non-governmental organisations (NGOs) and community-based organisations (CBOs) play an important role in health service provision. CHAT could be useful for resource allocation decisions within organisations like NGOs or CBOs- potentially empowering communities to drive their own solutions forward. This should be further explored.

7.3 Summary of Discussion

The above themes which are guided by the factors outlined in the conceptual framework are interconnected with the literature on evaluation of public engagement approaches. Established evaluation criteria are lacking, although there are some guiding criteria related to process and outcomes. My work explored elements of the process and outcomes of the CHAT exercise and could be extended. The process exploration considered the elements of the tool in terms of the information provided, the deliberations that took place and the engagement with trade-offs, as well as the way in which views and opinions were voiced and challenged. The outcomes that were explored were predominantly about the choices and values behind these choices, as well as individual characteristics associated with choices. While established evaluation criteria do not exist, it is important to consider process and outcomes more deeply to better understand the value of public engagement and to determine which public engagement methods are most appropriate. It is also important to define the goals of public engagement approaches upfront. Evaluations of public engagement should feedback into the methods and assist in determining which methods are appropriate for which goals. For meaningful public deliberation which aims to impact decision-making Balcksher’s components should be the starting point but should include the resource constraint element as demonstrated in my PhD. In addition, there should be consideration of specific goals (including which type of decision-making, and at what level); criteria for successful process and outcomes; and finally, the broader environment (political, social, economic) which links with equity and access barriers. Multiple methods might be necessary to reflect the range of publics and perspectives and to achieve the goals at different times. Transparency is important and should capture the details of any development/adaptation of the methods as well as plurality and dissenting views during implementation to fully appreciate the process and outcomes of public deliberation. Finally, institutionalisation of public engagement in priority setting at all levels could facilitate a cyclical dynamic and collaborative approach to engagement. This in turn would uphold the commitments to meaningful engagement as entrenched in the National Health Act and White Paper and protected in the Constitution, which ultimately could improve health outcomes.

7.4 Limitations of the study

The study was not without limitations. Some of these are mentioned already in the results chapters but are expanded upon here.

Modification and implementation of public deliberation tools is a resource and time intensive process. Although I was aware of this element from the outset, I had underestimated it. CHAT itself has many components that need to be developed for the tool to operate. The costing exercise in and of itself was complicated activity in a context of limited data availability and included a number of assumptions. The supporting materials and the translation requirements added to the complexity. This is one of the criticisms of public deliberations and may support views to avoid this. However, this is linked to the need to fully capture costs and benefits of these approaches. As well as the need to make provision for necessary budgets and expertise to reach vulnerable population in these deliberations.

The Demographic characteristics that I captured during CHAT implementation were limited and the analysis could have been enhanced if further characteristics were captured. For example, household composition and health status could have been useful. Some younger participants prioritised treatment for NCDs and it could have been valuable to know whether they were living with older parents/grandparents with NCDs. This would contribute to my understanding of the justifications behind the individual choices.

Some topics (like mental health) were not included in the CHAT board as the community did not prioritse this during the modification stage, and other areas (palliative care) were not prioritised during CHAT implementation. My sample size, however, was small and therefore I cannot conclude that these priorities are representative of rural South, but only of a particular rural community. Wider implementation is therefore necessary to understand priorities of broader groups. This is related to effectively capturing the voice of the vulnerable and excluded in public deliberation exercises. While the work captured voices of a particular vulnerable group, there are other vulnerable voices that were not represented. For example, people with disabilities, and mental health challenges. Including these voices may have led to different outcomes in terms of the topics that were included in the CHAT board as well as the final priorities.

Topics that were included in the final board may have differed at another point in time, or if other groups had participated. Malaria, for example, was prioritised for inclusion in the board as well as during implementation but reflected a particular point in time. Malaria outbreaks do not occur all the time in South Africa nor in Bushbuckridge. If the study had been conducted during a different point in time a different priority area would have likely emerged. While the final CHAT board was context specific, further implementation of CHAT in different parts of the country or with different groups would require additional modification. However, the initial steps that included the national level priority scoping can serve as a starting point and would not necessarily need to be replicated.

Another limitation was that the modification process at times relied on professional judgement. This applied to not only costing data but also in refining some of the interventions that were ultimately included in the final CHAT board. At the time of the modification of the board I was engaging closely with national level policymakers and the familiarity may have influenced some decisions inadvertently. The decision to exclude social determinants of health as a topic seemed reasonable in light of policy-makers within the DOH viewing these issues as outside their remit. A CHAT tool for SA that incorporates these social determinants of health and that informs multisectoral collaboration in priority setting could be useful in the future.

A further limitation, and one that would apply to all deliberative engagement exercises, is ‘tyranny of the majority” and group think. In this case, stronger voices may have overshadowed dissenting views. This highlights the importance of transparency and individual level follow up. Time and resource constraints, as discussed above, should be considered ahead of time to facilitate appropriate follow up.

7.5 Contributions of the research

There are several contributions that the work provides to the public engagement and priority setting field. The literature shows that there are a lack of appropriate frameworks, tools, and applications of meaningful public engagement especially in LMICs and with vulnerable populations. In addition, where public engagement does occur evaluation of process and outcomes is lacking. My work presents a context specific deliberative engagement tool for a rural community in South Africa and details of the participatory methods used for the adaption of this tool. In addition, it provides some insights into the process and outcome of the implementation with a vulnerable community. Finally, it presents an adapted framework that can be useful to inform a dynamic cyclical and collaborative approach for meaningful public engagement in priority setting for health.

This is the first time a deliberative tool for priority setting has been modified and implemented in the South African context and provides insight into the process and some of the outcomes of this approach within a vulnerable community. While the work provides specific insights from the CHAT tool and process specifically, it extends beyond this to public engagement in priority setting more broadly. The work shows that participatory methods are feasible in the modification of a public engagement tool like CHAT and can be applied in different country contexts in order to ensure these tools are relevant and acceptable thereby potentially strengthening the priority setting process. The modified CHAT tool can serve as a basis for further adjustments of CHAT for different settings in SA. The methods used in this modification are replicable and can be applied to further adaptations of CHAT or other engagement tools.

In terms of implementation of CHAT, this work demonstrates that deliberative approaches can offer vulnerable communities the opportunity to engage in difficult resource allocation decisions regarding health interventions. This work provides an example of how a rural community was able to grapple with resource allocation decisions, how they considered different perspectives and societal implications and were able to set priorities together. It presents some of the priorities of this particular rural community and the social values driving these choices, as well as some of the individual characteristics that might be important to consider when setting priorities.

The adapted conceptual framework for meaningful public engagement shows that different factors interrelate and impact one another. These factors include the different levels of decision making; the different perspectives that interact during decision making; the methods, and evaluation of the methods, that enable public engagement as well as the broader political, economic and social environment. The framework demonstrates that public engagement methods may change overtime, and that multiple methods might be required to capture various perspectives at different levels of decision making. The framework can be useful to inform a dynamic cyclical approach for meaningful public engagement and the various factors that ought to be considered for this approach.

Chapter 8

8 Conclusion and recommendations

8.1 Conclusion

SA remains committed to meaningful engagement as entrenched in its Constitution and supported by various policy documents. This thesis has demonstrated the potential benefit of meaningful public engagement in priority setting for health as the country aims to address its quadruple burden of disease and prevailing health inequities. The use of CHATs work provides an example of an approach that enables engagement with a vulnerable population around resource allocation and priority setting for health, and in so doing provides some insights into the practicalities of public engagement, especially with these vulnerable groups. It could be extended to make it more practical in the South African context and to impact policy. Tension exists between individual and group views. Even in the rural context which is characterized by collectivism and community cohesion there were some differences between individual and group views. Yet it was clear that participants were able to prioritise issues that did not reflect individual or family health needs. The participants were able to consider the community as a whole. The prioritization of curative services over preventative efforts highlights several things such as, the perceived lack of effectiveness of prevention, the high value attached to curative services and possibly the late stage that care is sought requiring curative and palliative care. This could be different in another setting in the country with better access to health care and especially preventive services and activities.

While the PhD showed that a deliberative process of public engagement is possible, the process of how this can impact on policy makers and the priority setting process in South Africa remains to be shown.

8.2 Implications for policy and practice

As South Africa is considering the structure and function of a priority setting institution to drive Universal Health Coverage, lessons from this work could guide the establishment of public engagement as an important component of this priority setting institution and the factors that need to be considered to move beyond tick box exercises. South Africa remains commitment to Health Technology Assessment as part of this priority setting institution and public engagement should be incorporated as embedded within HTA, not as a separate element. There is a window of opportunity for the structure of public engagement to be formalised and embedded as a core feature of decision making at the different levels. In terms of the actual health services package that is yet to be defined under UHC, the outcome of CHAT and further extension of the work could inform this package. Related to this, there is technical input that is being considered in defining the characteristics of a priority setting institution but experts in public engagement approaches are not included- this work could help fill this gap and speaks to the need to ensure all technical expertise are included. This relies on buy in from decision makers and requires advocacy to demonstrate the importance and potential benefit of incorporating public engagement expertise and approaches in priority setting institutions.

Decision makers should be held accountable to the commitments of meaningful public engagement in various policies and entrenched in the Constitution- the work provides guidance of how this could be achieved using public engagement tools. Related to this, provincial departments of health should adhere to the provision in the National Health Act which confers responsibility on them to develop legislation. This identifies the specific functions of the community health committees to ensure community participation in decision making. CHAT or other deliberative methods could contribute to elevating the role of CHCs so that they are a key feature of the decision-making process for local clinics. The process and outcomes of public engagement in decision-making must be documented with regular feedback to the public.

Because meaningful public deliberation can be costly and time intensive, there is a need to strengthen capacity and increase government investment in these approaches and expertise. This would ensure public engagement is sustainable. However, linked to this is the evaluation of public engagement methods and value for money of these approaches. Work should be supported in this area both in terms of resources and capacity to determine which engagement methods are most appropriate for which decisions.

Meaningful Public engagement should be extended to reach more of the public and should be supplemented with other deliberative and non-deliberative methods to enable this. Expertise in this field needs to be developed.

I recommend further engagement through the use of CHAT or another deliberative tool with decision makers at different levels (National and local), but also with Community Health Committees and NGOs/ Community-based Organisations. As these organisations are often responsible for provision of health (or health-related) services a tool such as CHAT could assist in including the communities in decision making around resource allocation with regard to these services, as well as in identifying challenges and solutions. In this way these organisations will be even more responsive to the needs on the ground and may be able to include their communities in resource allocation decisions.

8.3 Methodological considerations and future research

This work has addressed some of the gaps in the literature but has also highlighted key areas that require further investigation and could strengthen the public engagement in priority setting agenda. These include:

- Implementation of CHAT in different settings such as other rural communities as well as other marginalised groups and urban populations. This work could build on community engagement research including participatory action research that has already been conducted in these settings as starting point to identifying issues and solutions. CHAT could potentially be used as a next step to set priorities.

- Capturing of further demographic information and contextual issues when implementing CHAT or other deliberative engagement methods to develop existing knowledge of the factors that influence priorities of individuals.
- Further analyses post implementation of CHAT, or other engagement methods, to measure capacity development of participants and satisfaction levels.
- Expanding the CHAT work potentially through incorporation of other methods like DCE to reach a broader public. This could also potentially allow for consideration of the social determinants of health and resource allocation in regard to multi-sectoral interventions. In this way, CHAT could be extended to contribute to achieving “health in all policies” (although acknowledging the difficulty in costing multi-sectoral interventions).
- Conducting CHAT jointly with community members and local level decision makers. This could facilitate more of a collaborative shared decision-making approach. However, power dynamics would need to be addressed and buy in from decision makers and community members would need to be nurtured.
- Incorporation of cost effectiveness data in CHAT and exploration of how to represent CHAT information visually for illiterate communities.
- Further evaluation of the process and outcomes of CHAT as well as of other participatory engagement methods.
- Comparison of CHAT with other deliberative engagement methods to demonstrate which methods might be appropriate for which types of decisions. A case study that applies CHAT and another deliberative method like a citizen’s jury and documents the difference between the process and outcomes might be useful.

- Documenting the cost of modifying and implementing CHAT.
- Related to the above, performing a cost effectiveness analysis of CHAT and other deliberative methods
- Comparing the process and outcomes of my CHAT work with the CHAT that was implemented in rural India
- Exploring the applicability of CHAT to the private sector. Principles such as appropriateness, acceptability, transparency apply as much to the private sector as the public sector. Private medical aid schemes make decisions about health intervention coverage without any input from the people they cover and CHAT (or other engagement methods) may have a role to play in filling this gap.
- Engagement with different publics to compare different methods of public engagement or to develop new methods
- Exploring group and decision dynamics in deliberative engagement processes and how this influences the process and outcomes

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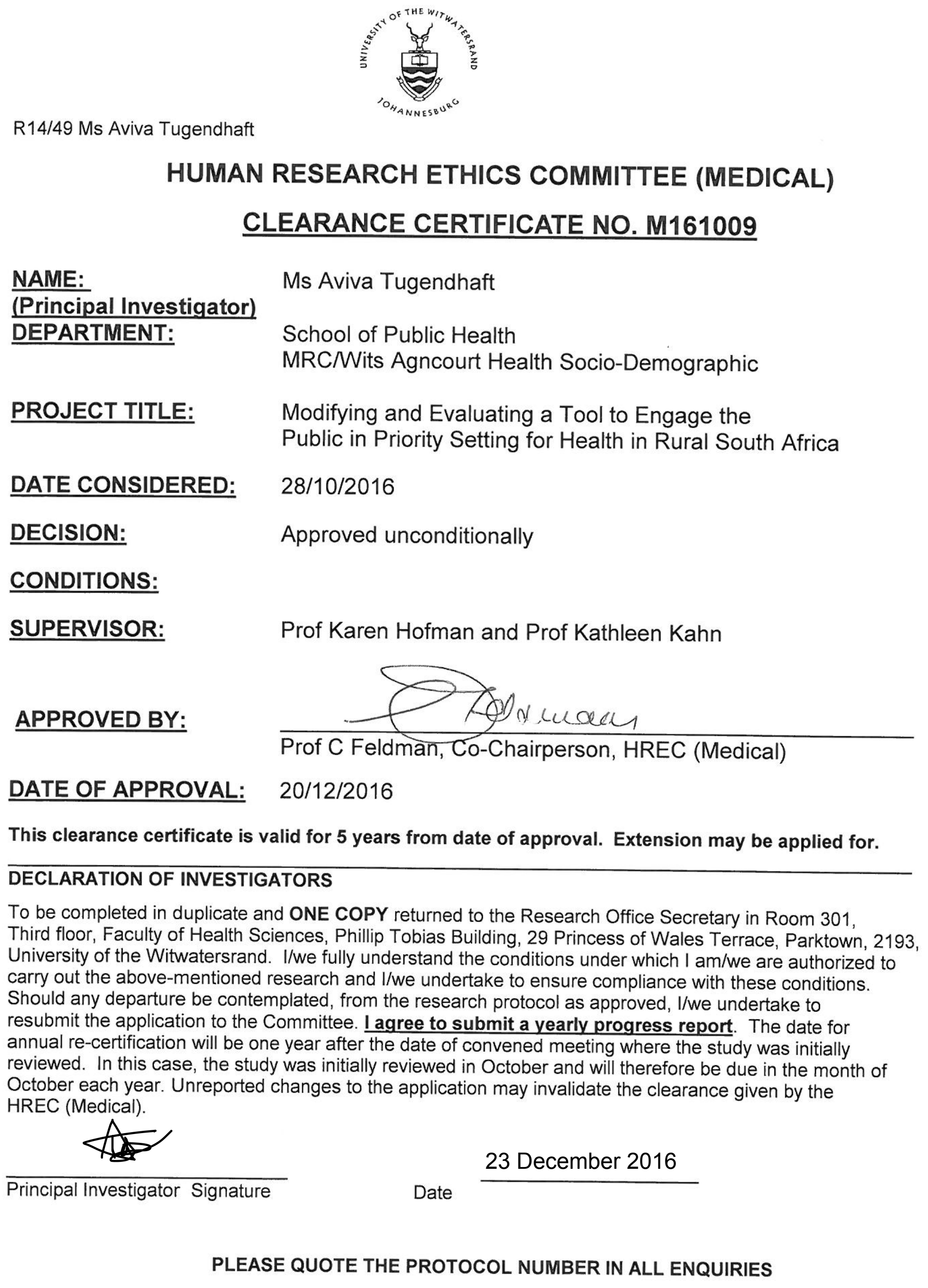
Appendices

APPENDIX A: Ethics Clearance certificate



R14/49 Ms Aviva Tugendhaft

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M161009

NAME: (Principal Investigator) Ms Aviva Tugendhaft

DEPARTMENT: School of Public Health
MRC/Wits Agncourt Health Socio-Demographic

PROJECT TITLE: Modifying and Evaluating a Tool to Engage the Public in Priority Setting for Health in Rural South Africa

DATE CONSIDERED: 28/10/2016

DECISION: Approved unconditionally

CONDITIONS:

SUPERVISOR: Prof Karen Hofman and Prof Kathleen Kahn

APPROVED BY: Prof C Feldman, Co-Chairperson, HREC (Medical)

DATE OF APPROVAL: 20/12/2016

This clearance certificate is valid for 5 years from date of approval. Extension may be applied for.

DECLARATION OF INVESTIGATORS

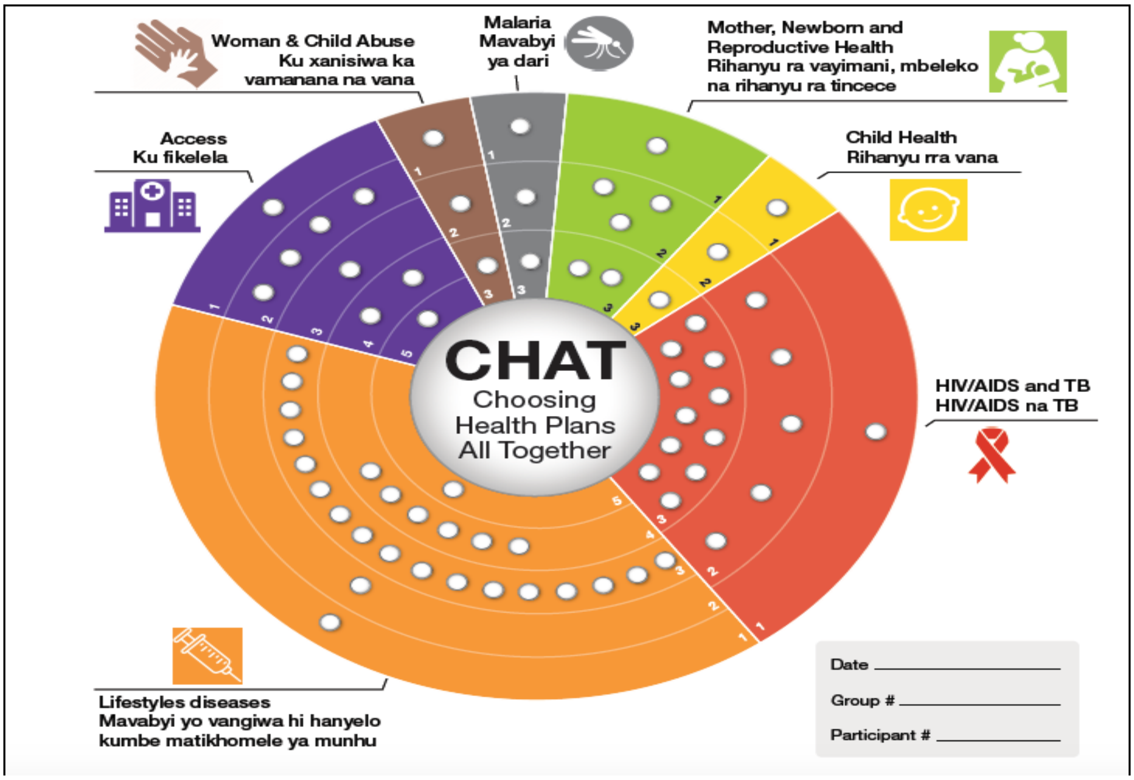
To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary in Room 301, Third floor, Faculty of Health Sciences, Phillip Tobias Building, 29 Princess of Wales Terrace, Parktown, 2193, University of the Witwatersrand. I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report**. The date for annual re-certification will be one year after the date of convened meeting where the study was initially reviewed. In this case, the study was initially reviewed in October and will therefore be due in the month of October each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature

Date 23 December 2016

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES

APPENDIX B: CHAT SA tool, as adapted for use in Bushbuckridge South Africa



APPENDIX C: Facilitator script

CHAT
"**C**hoosing**A**ll **T**ogether"
FACILITATOR SCRIPT

This version of CHAT was prepared in collaboration with the NIH of the US. Public Health Service and PRICELESS SA, Wits University

Note to Facilitator: Read the regular print out loud. The italicized print in parentheses *provides the facilitator directions that are not meant to be read aloud*

Introduction

(Prepare the room as follows: For each player lay out a packet containing two paper CHAT boards, two sets of stickers, an information manual and a pre- and post-exercise survey. Each of these packets and the material in them should be labeled with an assigned study number. Place the large CHAT board in the middle (or in sight of all participants) and have large stickers for use on the large board. If the session will be tape recorded, have the tape in the recorder ready to be turned on)

You each have a participant consent form in front of you which we need you to sign before we can begin- this is how you agree to participate in the study. You also have a form that says that you agree we can audio and video record the exercise today. I will read the forms to you and ask you to sign if you agree.

(Read the participant consent form and the audio/video consent form, make sure all participants sign both forms before beginning)

The information we collect from this exercise will be very helpful to us in understanding which health services are important to you. This project is an opportunity for you to voice your views about health services and we will try and feedback these views to the government who decides which services to provide. Thank you for taking the time to share this experience with us. We will answer all your questions as we go along. We hope you have fun.

You have each been given a packet of CHAT materials. Please note that we will collect this material at the end of the session, to use it with other groups. I will read these materials to you. We will know your choices later, when we have replies of many groups, by referring only to the study and participants number on these papers *(point out the number on the papers)*. This way we will protect your privacy. We ask all of you to also keep private information you hear from each other during the game –private; please do not repeat what you heard after you leave this session.

OK, we will begin by filling out the first questionnaire. I will read each question and you can select the answer that fits best for you.

*(**READ** each question and all the answers and make sure participants feel comfortable and understand how to answer each question.)*

Thank you for answering the questionnaire.
Now as we begin the CHAT exercise, let me tell you a bit about the health service package.

Sometimes people in your household become ill. When this happens, you try to help them as best you can. You take them to the clinic to get medicine. If you do not go to the clinic or get medicine your family member may be ill longer. If the illness gets terribly bad, your family member must go to the hospital. Sometimes people need to take medicine for their whole life, like if they have a chronic lifestyle disease like diabetes. The government tries to provide health services for everybody to make sure that those people who are sick are able to get the care and support that they need. The government also tries to stop people from getting sick in the first place by running things like education campaigns. All these things cost the government money and just like in every country in the world, there sometimes isn’t enough money to pay for all the services that we need. The government needs to decide which health services are the most important and where they should spend their money. It’s the same as when you go to the shops. You have some money at the end of the month, and you go to the shops to buy food for your family. You don’t have enough money to buy everything, so you need to decide between milk, cereal, tinned food, meat etc. These are the choices that you make. In the same way, the government has to choose which health services to provide.

So, in this exercise we want you to think about which health services you would like to see included in a health package. For example, it could be education and information for HIV/AIDS and TB or prevention and screening for lifestyle diseases, or you may think things like clinics being open for longer hours is important. You will make choices using the stickers that are available to you. The stickers are the money that is available, and you will only be able to select as many options as the stickers can cover. We hope this exercise will help you to understand that not everything can be provided and will help you to choose the things that are most important.

As we begin, let me give you some instructions:

Purpose

The purpose of CHAT is to help people to choose the components of a health service package that they prefer, and think are most important.

Taking part in CHAT

There are three Rounds in this CHAT exercise.

- In the First Round, each of you will make a health package that you think is best for you and your **family**.
- In the Second Round you will all work together to make a health package for a **whole community** (all people living in Bushbuckridge).
- In the Third Round you will again make a health package for **you and your family**, using all you learned as you took part in the second round.

FIRST ROUND

Step 1. You determine your ideal Health Service Package for you and your family

Let's start with the first Round. Does everyone have a **CHAT Exercise Board, CHAT Booklet,** and **35 stickers**? - *(Hold up **CHAT Game Board, CHAT Booklet** and **Stickers**.)* Your **CHAT Board** has 7 health service areas and in each of these areas there are different options to choose from, for example- education and information or prevention and screening or treatment. I will show you the picture, the color, and the name of each of the service areas *(Hold up the large CHAT Board and point to icon and name of each service area while reading the names out loud.) (Hold up **CHAT Booklet**.)* Your **CHAT Booklet** explains these different services and the different options. *(Open the CHAT booklet, point to the icon for each health service area and read the description of each option).* Before you decide which services to pick from the board you must make sure you have read the booklet explaining the different components of the services. During the game if anyone needs help looking for things in the booklet please ask and we will help

*(Hold up **Stickers**.)* You make your choices by pasting stickers on the CHAT Board. This is why we give you **35 Stickers** to paste. You can only choose services so long as you have stickers, so the game is to choose the health services you want most with the number of stickers you have.

For each health service you might choose to take it or leave it. Some services do not cost very much and only need 1 sticker while others cost more and need more sticker *(Demonstrate the different options on the **CHAT Board**.)*.

Let's begin Round One. **Remember that you are making a package just for you and your family in round 1-** Put your Stickers on your CHAT Board selections. Make the package you like using all the Stickers you have. **You can decide to change your mind and move around your stickers at any point during round 1-** Choose by yourself. Work on your own but if you need any help or advice using the board and the booklet please ask and we will be happy to help. You can take about 15 minutes for this step. Go ahead; begin.

*(**PAUSE.** Allow players time to work. Be available to answer questions. Let players know when there are only a few minutes left. After about 15 minutes say)*

Step 2. Test Your Health Package

Okay. **Now that you finished making your choices you can't change them anymore in this round-** Let's test your package. You can see the results of the choices you picked by picking the CHAT health event cards. Each person will have a turn taking a card. Each of your cards relates to one of the health services on the board. On the back of the card, you will find a medical problem you might face. I will read your Event Card, or you can read your event card yourself. Some Event Cards are about men or women or children. After we read your event card, please share your thoughts about how the health package you have designed in round 1 would help the medical problem or not **and what might be important to the broader community in BBR-** As you listen to the different medical stories on each card, you'll get a better and better idea of what is important and what you want the health package to include.

Now each person takes a card.

*(**PAUSE.** Probe with additional questions such as: Did you package work the way you expected it to work? Would you consider changing your priorities? making different choices in the future? After completion of Round One, go to Round Two)*

SECOND ROUND

We've completed the First Round and will now move on to the Second Round. Now we'll "Choose a Health package All Together" as one big group. **Now please think about a package of health services that is for everyone in the community, not just for your family.** To do this, we'll use this Big CHAT Board *(Point to Board).*

We'll each take turns saying what we prefer and try to convince the group to agree. We'll go around the table asking each person to choose an option within one of the health service areas. We will ask you to tell us why you make this choice and allow others to comment. If others agree, I'll place stickers, on the Big CHAT Board. If someone disagrees with a suggestion, please raise your hand and tell us why. We will decide together whether it is a good idea to add the option and we will vote whether to include it.

*(**PAUSE** for questions.)*

Let's begin making our recommendations. *(Pick a person to start.),* Let's begin with you. What health service area and which option would you like to select? Why do you select this? *(Important to remember to ask WHY the participants select the options that they do and for fieldworkers to note)*

*(**PAUSE.** After completion of the second Round, go to the Third Round and say:)*

Third ROUND

Now let's move to the Third and last Round.

In this Round, each of you will repeat what you did in Round One: you'll make a choice on your own **to create a package for you and your family again.** With all that you've heard and thought about playing this game, take about 10 minutes to make the selection of services, using your **35 Stickers** and your **CHAT Board**. Once again, work on your own but please ask for help if you need it. Begin.

*(**PAUSE.** Allow players time to work. After about 5 minutes say:)*

If you're finished, please wait for the Post exercise questionnaire.

Now, let's complete the questionnaire. I will read each question and you can check the answer that fits best for you.

*(**READ** each question and all the answers and make sure participants feel comfortable and understand how to answer each question.)*

Thank you for participating in the CHAT exercise. We hope you enjoyed it.

POST-EXERCISE DEBRIEFING IF TIME ALLOWS

(To make this a valuable debriefing, be prepared to probe the debriefing questions with follow up questions such as: Why? Why not? What do you mean? How do others feel about this?)

Now that you've participated in the CHAT exercise, we'd like to know

- What did you think of it?
- What about the exercise did you enjoy?
- What did you not enjoy about the exercise?
- Do you remember at the beginning, we said the purpose of CHAT was to help people to choose the components of a health service package that they prefer, and think are most important. Do you think this exercise succeeded? Did it help you to make these choices?
- What do you think about the final package made by the group? (Would you want this same package for your family?)

(As Facilitator, take cues from statements of Participants.)

(**PAUSE.** *Allow time for general critique of the exercise and discussion of the exercise's success in achieving its purpose. Then say:)*

We hope you enjoyed the CHAT exercise. Thank You very much for joining in!

APPENDIX D: Information sheet to participate in the CHAT exercise

STUDY TITLE: Engaging the public in priority setting for health in a rural setting in South Africa

RESEARCHER'S NAME & AFFILIATION: Aviva Tugendhaft, PRICELESS SA, School of Public Health, University of the Witwatersrand

This informed consent may contain words that you may not understand. Kindly ask study staff to explain these words or anything that you do not understand. You may go home with a copy that was not signed to think about it or discuss with family or friends before you decide

INTRODUCTION

Good day my name is ____________. I am a researcher linked to the Wits School of Public Health. This study is taking place in Bushbuckridge to test whether a method called CHAT (choosing Health plans All Together) is a good way of helping the community and individuals to choose health services that are important to them. The main researcher, Ms Aviva Tugendhaft is a student at the University of the Witwatersrand in Johannesburg.

You are being invited to participate in this study as a member of the community. Before you agree to participate in this study, you need to fully understand what is asked of you and to be sure you are completely happy with what is involved. If you do not understand the information or have any other questions, feel free to ask.

PURPOSE OF THE STUDY AND YOUR PARTICIPATION

If you decide to participate in the study, you will be asked to answer a few questions about your income, your health and about which health services you think are most important. You will also be asked to participate in a game-like exercise with other members of the community that will take place over half a day in one of the nearby villages. During the game you will be given a choice of health services and you will have to pick those ones that you feel are most important. You may also be asked to participate in an interview after the game where the researchers will ask you more detailed questions about what you thought of the game. The game and the interview will be audio and video recorded, and the research team will listen to and watch what you and others have said so that we can understand more about what the community thinks are most important for health care, and about how this game might be useful for the community to make decisions about health services. This study involves the audio and video recording of your participation in the CHAT exercise. The research team will be able to listen to and watch the recordings. The audio tapes will be transcribed by the researcher and will be used for this research study. Transcripts may be reproduced in whole or in part for use in presentations or written products that result from this study.

CONFIDENTIALITY

You will not be expected to share personal information like your name. This means that anything that is used from what you say during the study cannot be linked back to you by the researchers. But because you will be participating alongside others in this exercise we cannot guarantee that the information you give us will remain confidential as this information will be shared with the other participants

Neither your name nor any other identifying information will be connected with the recording or the transcript.

You will not be identified by name in any of the reports or publications of this study or its results.

The information that is collected will be used for educational and scientific purposes related to this study and will be stored in a locked office at the Wits School of Public Health during the study. Audio recordings will be stored in a locked office at the Wits School of Public Health for a minimum of two years after publications resulting from the study or 6 years in the absence of publication, as per HPCSA (Health Professions Council of SA) guidelines

POTENTIAL BENEFITS

There are no direct benefits to you from this study.

COSTS AND COMPENSATION

There is no cost to you for being in this study. However, transport will be provided on the day of the exercise, or if you use your own transport, the costs will be reimbursed to you.

RIGHTS AS A PARTICIPANT

Taking part in this study is completely your choice. You can stop participating in the study at any time, even if you have already agreed to participate. Please remember that you are also free to skip over any question you do not want to answer, or you may decide to remain quiet in some parts of the CHAT exercise. You can also stop answering questions at any time or participating in the CHAT exercise even if you have already begun. By agreeing to participate you must feel comfortable with the exercise being audiotaped and if you are not comfortable with this you can choose not to participate without any negative repercussions.

If you have any questions about the study, you can ask the fieldworker who gave you this form or you can contact the researcher Ms Aviva Tugendhaft by email or phone: aviva.tugendhaft@wits.ac.za 0828291025

This study has received ethical approval from the University of the Witwatersrand. If you have questions about your rights as a research participant or complaints about the manner in which you were treated, or feel that study has caused you harm, please contact:
Prof. Peter Cleaton-Jones, Chairperson for the Committee for Human Research Ethics Committee University of the Witwatersrand. Tel: 011 717 2301

APPENDIX E: Information sheet for district/provincial policymaker/expert to participate in a focus group discussion

STUDY TITLE: Engaging the public in priority setting for health in a rural setting in South Africa

RESEARCHER'S NAME & AFFILIATION: Aviva Tugendhaft, PRICELESS SA, School of Public Health, University of the Witwatersrand

INTRODUCTION

Good day my name is ____________. I am a researcher linked to the Wits School of Public Health. This study is being undertaken with the community in Bushbuckridge and with experts and national, provincial and district level policymakers to modify and evaluate a tool to engage the community in priority setting for health in South Africa. The researcher, Ms Aviva Tugendhaft is a student at the University of the Witwatersrand in Johannesburg.

PURPOSE OF STUDY AND YOUR PARTICIPATION

You are being invited to participate in this study as a policymaker/ expert. If you decide to participate in the study, you will be asked to participate in a focus group and a Delphi exercise with other policymakers/experts. In the focus group you will be asked what you think of a specific tool to engage the public in priority setting for health. You will also be asked questions about which health services/ interventions are most important for consideration in defining a health service package. Finally, you will be asked to rank rate a set of interventions at the end of the focus group. Your answers will be considered in modifying a public engagement tool called CHAT (Choosing Health plans All Together) to implement and evaluate in Bushbuckridge. The focus group will be audio recorded, and the tapes will be transcribed and analysed qualitatively to determine the views of policymakers and experts with regard to health interventions that are important in the design of a health service package and the view of public engagement in priority setting for health using the modified CHAT tool. Transcripts may be reproduced in whole or in part for use in presentations or written products that result from this study.

CONFIDENTIALITY

The information that you will give will be used for educational and scientific purposes and the researchers have been trained in respecting your privacy. However, because you will be participating within a focus group alongside other experts' confidentiality cannot be guaranteed. Neither your name nor any other identifying information will be connected with the audio recording or the transcript You will not be identified by name in any of the reports or publications of this study or its results. The information gathered will be stored in a locked office at the Wits School of Public Health for the duration of the study and the analyses that follow relating to the study. Audio recordings will be stored in a locked office at the Wits School of Public Health for a minimum of two years after publications resulting from the study or 6 years in the absence of publication, as per HPCSA (Health Professions Council of SA) guidelines

POTENTIAL BENEFITS

There are no direct benefits to you from this study.

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COSTS AND COMPENSATION

There is no cost to you of being in this study, but you will be reimbursed for travel costs to the meeting.

RIGHTS AS A PARTICIPANT

Taking part in this study is completely voluntary. You can stop participating in the study at any time, even if you have already given your consent, without any negative implications. You can also refuse to answer any of the guiding questions at any point or you may choose to remain quiet during parts of the focus group discussion.

If you have any questions about the study, researcher Ms Aviva Tugendhaft by email or phone: aviva.tugendhaft@wits.ac.za 0828291025

This study has received ethical approval from the University of the Witwatersrand. If you have questions about your rights as a research participant or complaints about the manner in which you were treated, or feel that study has caused you harm, please contact:
Prof. Peter Cleaton-Jones Chairperson for the Committee for Human Research Ethics Committee University of the Witwatersrand
Tel: 011 717 2301

APPENDIX F: Information sheet for home-based carers to participate in a focus group discussion

STUDY TITLE: Engaging the public in priority setting for health in a rural setting in South Africa

RESEARCHER'S NAME & AFFILIATION: Aviva Tugendhaft, PRICELESS SA, School of Public Health, University of the Witwatersrand

INTRODUCTION
Good day my name is ____________. I am a researcher linked to the Wits School of Public Health. This study is being undertaken with the community in Bushbuckridge and with experts and national, provincial and district level policymakers to modify and evaluate a tool to engage the community in priority setting for health in South Africa. The researcher, Ms Aviva Tugendhaft is a student at the University of the Witwatersrand in Johannesburg.

PURPOSE OF STUDY AND YOUR PARTICIPATION
You are being invited to participate in this study as a home bases carer. If you decide to participate in the study, you will be asked to participate in a focus group and a Delphi exercise with other home-based carers from Bushbuckridge. In the focus group you will be asked what you think of a specific tool to engage the public in priority setting for health. You will also be asked questions about which health issues and services/ interventions are most important for Bushbukridge. Finally, you will be asked to rank rate a set of health services/ interventions at the end of the focus group and again with a follow up sms. Your answers will be considered in modifying a public engagement tool called CHAT (Choosing Health plans All Together) to implement and evaluate in Bushbuckridge. The focus group will be audio recorded, and the tapes will be transcribed and analysed qualitatively to decide which interventions to include in the CHAT board to implement in bushbuckridge. Transcripts may be reproduced in whole or in part for use in presentations or written products that result from this study.

CONFIDENTIALITY
The information that you will give will be used for educational and scientific purposes and the researchers have been trained in respecting your privacy. However, because you will be participating within a focus group alongside other home-based carers confidentiality cannot be guaranteed. Neither your name nor any other identifying information will be connected with the audio recording or the transcript You will not be identified by name in any of the reports or publications of this study or its results. The information gathered will be stored in a locked office at the Wits School of Public Health for the duration of the study and the analyses that follow relating to the study. Audio recordings will be stored in a locked office at the Wits School of Public Health for a minimum of two years after publications resulting from the study or 6 years in the absence of publication, as per HPCSA (Health Professions Council of SA) guidelines

POTENTIAL BENEFITS
There are no direct benefits to you from this study.
COSTS AND COMPENSATION
There is no cost to you of being in this study, but you will be reimbursed for travel costs to the meeting.

RIGHTS AS A PARTICIPANT
Taking part in this study is completely voluntary. You can stop participating in the study at any time, even if you have already given your consent, without any negative implications.

You can also refuse to answer any of the guiding questions at any point or you may choose to remain quiet during parts of the focus group discussion.

If you have any questions about the study, researcher Ms Aviva Tugendhaft by email or phone: aviva.tugendhaft@wits.ac.za 0828291025

This study has received ethical approval from the University of the Witwatersrand. If you have questions about your rights as a research participant or complaints about the manner in which you were treated, or feel that study has caused you harm, please contact:
Prof. Peter Cleaton-Jones Chairperson for the Committee for Human Research Ethics Committee University of the Witwatersrand
Tel: 011 717 2301

APPENDIX G: Participant Consent form

STUDY NAME: Engaging the public in priority setting for health in a rural setting in South Africa

RESEARCHER'S NAME & AFFILIATION: Aviva Tugendhaft, PRICELESS SA, School of Public Health, University of the Witwatersrand

I ____________________________ have read the participant information sheet and I understand it.

I was given a chance to ask questions and had them answered.

I understand that the researchers will take measures to maintain my privacy, but that confidentiality cannot be guaranteed because I will be participating as part of a group with other participants during the study

I agree that information gathered in this study may be stored anonymously and securely and may be used for the purpose of this study.

I understand that it is my choice to participate and that I am free to stop participating without giving a reason.

I agree to take part in this study

Signature of participant __________________________________

Signature of researcher/ fieldworker _____________________________

Date _________________________________

APPENDIX H: consent to audio recording & transcription for CHAT participant

STUDY NAME: Engaging the public in priority setting for health in a rural setting in South Africa

RESEARCHER’S NAME & AFFILIATION: Aviva Tugendhaft, PRICELESS SA, School of Public Health, University of the Witwatersrand
The participant information sheet has explained that this study involves the audio recording of your participation in the CHAT exercise. Neither your name nor any other identifying information will be connected with the audio recording or the transcript. The research team will be able to listen to the recordings. The audiotapes will be transcribed by the researcher and will used for this research. Transcripts may be reproduced in whole or in part for use in presentations or written products that result from this study. Audio recordings will be stored in a locked office at the Wits School of Public Health for a minimum of two years after publications resulting from the study or 6 years in the absence of publication, as per HPCSA (Health Professions Council of SA) guidelines

By signing this form, I am allowing the researcher to audio and video record me as part of this research.

Participant's Signature:

____Date: ___________

Fieldworker/researcher signature

____Date: ____________

APPENDIX I: Consent to audio recording & transcription for focus group participant

STUDY NAME: Engaging the public in priority setting for health in a rural setting in South Africa

RESEARCHER'S NAME & AFFILIATION: Aviva Tugendhaft, PRICELESS SA, School of Public Health, University of the Witwatersrand
The participant information sheet has explained that this study involves the audio your participation in the focus group. Neither your name nor any other identifying information will be connected with the audio recording or the transcript. The research team will be able to listen to the recordings. The audiotapes will be transcribed by the researcher and will used for this research. Transcripts may be reproduced in whole or in part for use in presentations or written products that result from this study.
Audio recordings will be stored in a locked office at the Wits School of Public Health for a minimum of two years after publications resulting from the study or 6 years in the absence of publication, as per HPCSA (Health Professions Council of SA) guidelines

By signing this form, I am allowing the researcher to audio record me as part of this research.

Participant's Signature:

____Date: ___________

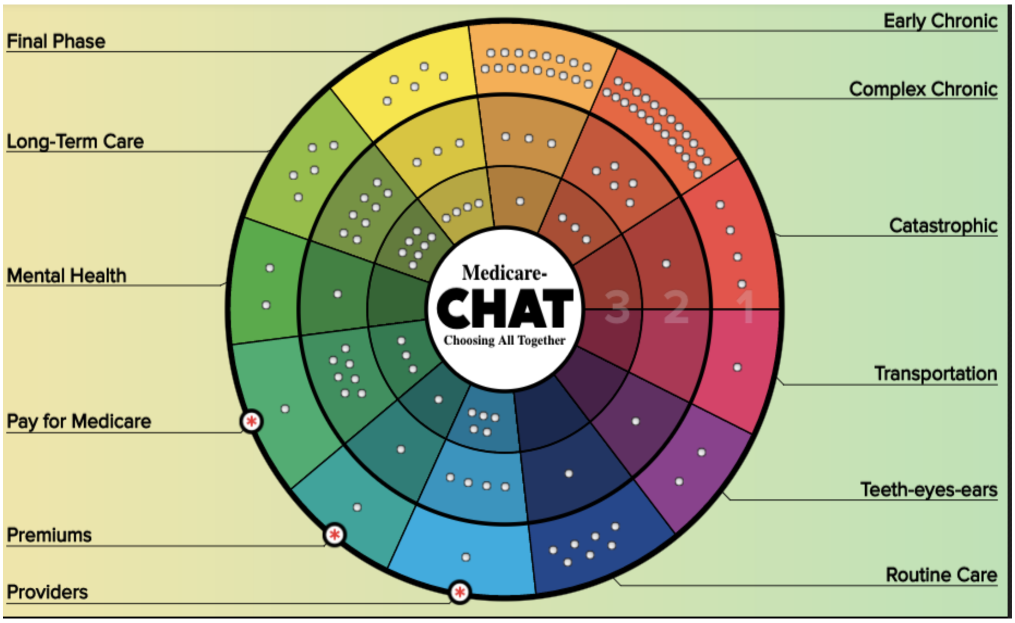
Fieldworker/researcher signature

____Date: ____________

APPENDIX J: Documents included in the desktop review

National policy documents
NHI White paper 2015
Budget speech 2017, transcript
Negotiated Service Delivery Agreement, 2010-2014
National Development Plan 2013-2030
The Primary Healthcare Package for SA, 2000
Department of Health Strategic Plan 2014-2019
Maternal, Newborn, Child and Women's Health and Nutrition Strategic Plan 2012-2016
South Africa's National Strategic Plan for a Campaign on Accelerated Reduction in Maternal Mortality in Africa (CARMMA), 2012
Adolescent and Youth Health Policy 2016-2020
National Plan of Action on Ageing 2006-2016
National Mental Health Policy Framework and Strategic Plan 2013-2020
Strategic Plan for the Prevention and Control of Non-Communicable Diseases 2013-17
Framework for Disability and Rehabilitation Services 2015-2020
Provincial policy documents
Mpumalanga Annual Performance Plan 2016/17
District policy documents
Ehlanzeni Distict Health Plan 2015

APPENDIX K: An original CHAT board



APPENDIX L: Plagiarism declaration

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

FACULTY OF
HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I Aviva Tugendhaft (Student number: 0409355J) am a student

registered for the degree of Doctor of Philosophy in the academic year 2023.

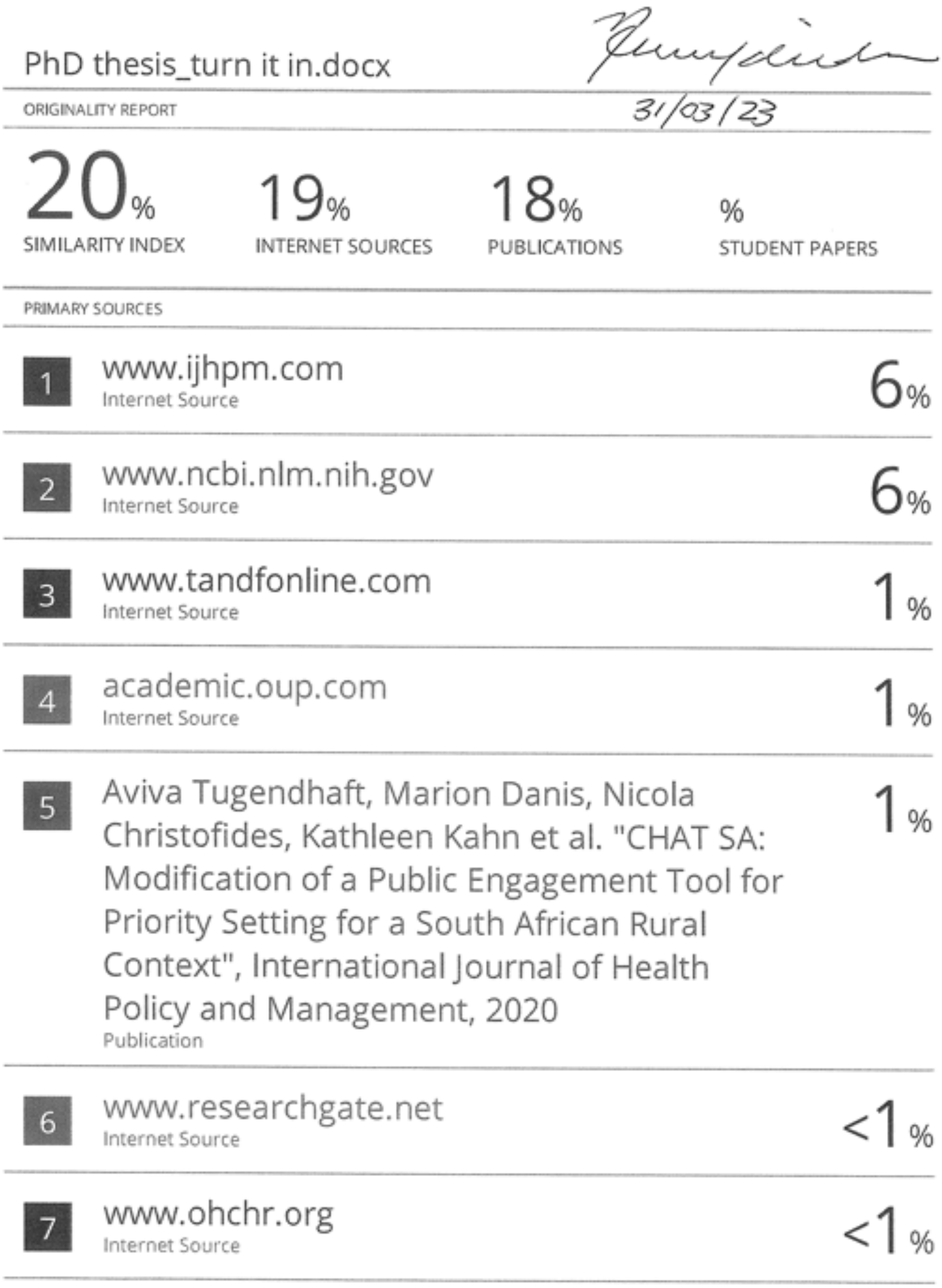
I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature: ______________________ Date: ~~31 March 2023~~ -- 3 October 2023

26/04/2015
1

APPENDIX M: Turn-it-in report



PhD thesis_turn it in.docx

31/03/23

ORIGINALITY REPORT

20%	19%	18%	%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

PRIMARY SOURCES

1	www.ijhpm.com Internet Source	6%
2	www.ncbi.nlm.nih.gov Internet Source	6%
3	www.tandfonline.com Internet Source	1%
4	academic.oup.com Internet Source	1%
5	Aviva Tugendhaft, Marion Danis, Nicola Christofides, Kathleen Kahn et al. "CHAT SA: Modification of a Public Engagement Tool for Priority Setting for a South African Rural Context", International Journal of Health Policy and Management, 2020 Publication	1%
6	www.researchgate.net Internet Source	<1%
7	www.ohchr.org Internet Source	<1%