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a scoping review on research priorities

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Publication date

2021

Document Version

Final published version

Published in

Health Policy and Planning

License

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Citation for published version (APA):

Myburgh, H., Reynolds, L., Hoddinott, G., van Aswegen, D., Grobbelaar, N., Gunst, C., Jennings, K., Kruger, J., Louis, F., Mubekapi-Musadaidzwa, C., Viljoen, L., Wademan, D., & Bock, P. (2021). Implementing 'universal' access to antiretroviral treatment in South Africa: a scoping review on research priorities. *Health Policy and Planning*, 36(6), 923-938. <https://academic.oup.com/heapol/article/36/6/923/6272130>

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Implementing ‘universal’ access to antiretroviral treatment in South Africa: a scoping review on research priorities

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Accepted on 31 July 2020

Abstract

‘Universal’ access to antiretroviral treatment (ART) has become the global standard for treating people living with HIV and achieving epidemic control; yet, findings from numerous ‘test and treat’ trials and implementation studies in sub-Saharan Africa suggest that bringing ‘universal’ access to ART to scale is more complex than anticipated. Using South Africa as a case example, we describe the research priorities and foci in the literature on expanded ART access. To do so, we adapted Arksey and O’Malley’s six-stage scoping review framework to describe the peer-reviewed literature and opinion pieces on expanding access to ART in South Africa between 2000 and 2017. Data collection included systematic searches of two databases and hand-searching of a sub-sample of reference lists. We used an adapted socio-ecological thematic framework to categorize data according to where it located the challenges and opportunities of expanded ART eligibility: individual/client, health worker–client relationship, clinic/community context, health systems infrastructure and/or policy context. We included 194 research articles and 23 opinion pieces, of 1512 identified, addressing expanded ART access in South Africa. The peer-reviewed literature focused on the individual and health systems infrastructure; opinion pieces focused on changing roles of individuals, communities and health services implementers. We contextualized our findings through a consultative process with a group of researchers, HIV clinicians

KEY MESSAGES

- The 194 research articles identified in this scoping review of the challenges and opportunities of expanded antiretroviral treatment (ART) access in South Africa predominantly reported on individual-level and health systems infrastructure factors. This indicates that research on this subject is skewed towards understanding expanded ART access in South Africa in terms of individual-level factors that impact engagements along the HIV care continuum (such as age, gender, CD4 count and key population groups) and health systems infrastructure challenges (such as task shifting, staff shortages and the need for innovative models of care).
- The disproportionate underrepresentation of interpersonal and social dynamics in expanding ART access in South Africa mirrors their perceived importance in the country's epidemic response. These dynamics matter for programme scale-up as HIV is a distinctly social disease, with transmission taking place in the most intimate aspects of human life (e.g. intimate sexual relationships and between mother and child), and management of treatment requiring a lifelong relationship with the health service. Lack of attention to these interpersonal and social dynamics limits understanding of how they can be intervened upon to support and scale-up the programme.
- Multidisciplinary approaches to HIV research that draw from broader literature in the social sciences and focus on the social dynamics of communities and of health services will strengthen analyses of the challenges facing HIV programme expansion and of opportunities to support it.

and programme managers to consider critical knowledge gaps. Unlike the published literature, the consultative process offered particular insights into the importance of researching and intervening in the relational aspects of HIV service delivery as South Africa's HIV programme expands. An overwhelming focus on individual and health systems infrastructure factors in the published literature on expanded ART access in South Africa may skew understanding of HIV programme shortfalls away from the relational aspects of HIV services delivery and delay progress with finding ways to leverage non-medical modalities for achieving HIV epidemic control.

Keywords: Universal test and treat, ART scale-up, HIV/AIDS, South Africa, review

Introduction

There is growing evidence that early and widespread antiretroviral treatment (ART) with sustained adherence reduces the likelihood of HIV transmission and improves clinical outcomes for people living with HIV (PLHIV) (Granich *et al.*, 2009; Dodd *et al.*, 2010; Cohen *et al.*, 2011; Eaton *et al.*, 2014). In the wake of these findings, the World Health Organization (WHO) released revised ART guidelines in 2015 stipulating initiation of ART in everyone living with HIV, at any CD4 cell count (WHO, 2015). Immediate initiation of and 'universal' access to ART has since become the global standard for preventing and treating HIV (UNAIDS, 2015). Global HIV programmes such as the President's Emergency Plan for AIDS Relief (PEPFAR) and the Joint United Nations Programme on HIV/AIDS (UNAIDS) are supporting high-burden countries' urgent implementation of this new guideline to accelerate achieving epidemic control (the point at which the total number of new infections falls below the total number of deaths from all causes among HIV-positive individuals). Implementation of 'universal' access to ART is operationalized in the UNAIDS 90–90–90 targets, where 90% of PLHIV know their status, 90% of people diagnosed with HIV receive ART and 90% of those on ART are virally suppressed (UNAIDS, 2014; UNAIDS, 2015). These targets are globally accepted as measures of the performance of countries' HIV response and of their overall progress towards achieving epidemic control (UNAIDS, 2015; Sidibé *et al.*, 2016).

Over the last decade a number of 'universal test and treat' (UTT) trials implemented across sub-Saharan Africa have tested the real-world efficacy of 'universal' access to ART (Perriat *et al.*, 2018; Karim, 2019). The trial outcomes show that important increases in

the proportion of people who are virally suppressed are possible by implementing widespread ART (Karim, 2019). Yet, the trials failed to clearly demonstrate the significant reduction in new HIV infections at population level estimated in modelling studies and required for epidemic control (Iwuji *et al.*, 2018, Hayes *et al.*, 2019; Havlir *et al.*, 2019; Makhema *et al.*, 2019). While the trial findings indicate that 'universal' access to ART is a promising way forward in countries' HIV response, the findings also suggest that achieving the estimated real-world reductions in new HIV infections by bringing 'universal' access to ART to scale is more complex than anticipated (Cohen, 2019; Karim, 2019).

Following on these trial results, we suggest that this is an important moment to take stock of the assumptions that inform how ART availability and coverage are increased with implementation of 'universal' access to ART. In this article, we aim to review how the anticipated challenges and opportunities for scaling-up health services to offer 'universal' ART access are located in the HIV science literature. Using South Africa—the country with the largest number of PLHIV and the largest ART programme globally—as a focused case example, we present findings of a scoping review of the published scientific literature on expanding access to ART with a meta-commentary on how research is focused around this topic. Through this analysis, we consider how specific research priorities and foci may bias and limit how the HIV epidemic is understood and intervened upon and reflect on the critical knowledge and intervention gaps that such biases and limitations are likely to create.

With 7.97 million PLHIV in 2018 (Statistics South Africa, 2019), South Africa accounts for 21% of the global HIV burden and

14% of new HIV infections (UNAIDS, 2019). Since establishing a national ART programme in 2004, South Africa has been at the forefront of adopting global ART policy recommendations and has in many ways become a testing ground for what is possible in the HIV response in developing health settings (Nordling, 2016). South Africa was among the first African countries to adopt the policy of ‘universal’ access to ART following the WHO’s guideline recommendation and has officially been implementing the policy since September 2016 (National Department of Health, 2016). While successful implementation of the policy to offer ‘universal’ access to ART promises to significantly impact the South African HIV epidemic, it will also ambitiously require a near doubling of the number of people on ART, from 4.7 million people on treatment to ~8 million people estimated to be living with HIV (Statistics South Africa, 2019; UNAIDS, 2019). Achieving the current level of treatment availability and coverage has taken more than 15 years of intense domestic and international financial investments, massive social mobilization and commitment from all levels of government and civil society. Even with these efforts, South Africa’s national HIV programme is failing to achieve the UNAIDS 90–90–90 targets for epidemic control and has the highest number of new HIV infections per year (UNAIDS, 2019)—a major concern for global health researchers and policy makers (United States Department of State, 2019). The factors that are negatively impacting the success of South Africa’s HIV response are likely to intensify, at least in the short term, with the major expansion of ART services required for successful implementation of ‘universal’ access to ART. Our focused review of the scientific literature about expanding access to ART in South Africa allows us to carefully interrogate the local dynamics and particular assumptions that colour scientific knowledge production and programme implementation. Furthermore, the findings we present open up the possibility to similarly consider the structuring assumptions that underlie HIV science and the response to the epidemic in other local settings and worldwide.

Methods

This article is the collaborative work of researchers, clinicians and managers in South Africa’s HIV programme. These include social scientists with disciplinary backgrounds in sociology, anthropology, psychology and public health and HIV clinicians, implementers and programme managers involved in the HPTN 071 (PopART) trial, the largest UTT trial to date, which was implemented in the Western Cape Province of South Africa and across Zambia from 2013 to 2018 (Hayes *et al.*, 2014, 2019). We draw on our expertise of implementing ‘universal’ access to ART in South Africa specifically to consider the challenges and opportunities of scaling-up the ART programme towards an eventual goal of ‘universal’ access to ART.

The WHO (2007, p. 12) identifies three dimensions of treatment access, comprising availability, coverage and impact. For treatment to be available requires it to be physically reachable, economically affordable and socio-culturally acceptable; coverage is defined by the ‘proportion of a population needing an intervention who receive it’ and impact is measured by the efficacy and effectiveness of the intervention to reduce infection and mortality rates. ‘Universal’ access to ART then means that treatment is available (reachable, affordable and acceptable) to every person living with HIV, that every person living with HIV receives the treatment they need (coverage) and lastly, that treatment availability and coverage impacts on the infection and mortality rates of the epidemic. In this article, we focus on the availability and coverage dimensions of treatment access and centre our analysis of the literature on how the HIV programme is

scaled-up to start and keep more PLHIV on ART. We refer to ‘universal’ treatment access using quotation marks to acknowledge and remind readers that even with the best implementation efforts and political will, treatment access, coverage and impact remains unequal for different populations and marginalized groups.

We use a scoping review methodology to describe the peer-reviewed literature, including opinion pieces, with particular focus on expanding HIV services to implement ‘universal’ access to ART. Scoping reviews fulfil a particular methodological gap (Arksey and O’Malley, 2005; Levac *et al.*, 2010) well suited to the aims of this paper; it allowed us to iteratively and reflexively examine and ‘map’ the range and nature of research activities on expanding access to HIV services in South Africa. We combined the scoping review with a consultative process with collaborating researchers on the PopART trial and clinicians, implementers and managers in the HIV programme to critically consider the value of and gaps in the scientific literature on expanding ART services to achieve ‘universal’ access to ART. As Arksey and O’Malley (2005) point out, consultative processes are considered to enhance the usefulness of scoping review results by having practitioners and research consumers contribute to the work. Our purpose in following this scoping review design is one of ‘hypothesis generation’ (Henwood and Pidgeon, 1992; Finlay, 2006) to enable consideration of the implications of our findings for future research and programming. The review and initial analysis were conducted exclusively by the first four authors, all social scientists working on the PopART trial. Other collaborators participated through their involvement in at least one of our two consultative processes and through their contributions to the writing of this article, as described in more detail in this section.

Identifying results

Our review included scientific literature published in peer-reviewed journals between January 2000 and December 2017. In addition to peer-reviewed research articles, we also included opinion pieces published in scientific journals as they offer important insights on the state of the ART programme in South Africa. The timeframe was selected to include a number of major policy and programmatic changes around access to ART in South Africa, from ART eligibility dependent on CD4 cell count and WHO staging, to ‘universal’ ART. This includes the establishment of a national prevention of mother to child transmission (PMTCT) programme in 2002 (Barron *et al.*, 2013), preparation of accredited ART sites (National Department of Health, 2003), national roll-out of the ART programme in 2004 (National Department of Health, 2004), and continued adoption of more inclusive ART eligibility criteria over the course of the programme’s expansion from 2005 to 2016 (Health Systems Trust, 2012; National Department of Health, 2010; National Department of Health, 2015; National Department of Health, 2016). This timeframe is relevant to our analysis as much of the research and policy focus post-2017 has shifted away from concerns with ART scale-up and the rationale for ‘universal’ treatment and towards the impact of ART on the epidemiology of HIV.

As a first step in our review, the first and fourth authors conducted three literature searches: one broad search in the PubMed database using medical subject headings (MESH) and two narrow searches using keywords related to ‘universal’ access to ART in both the PubMed and EBSCOhost databases. We developed keywords with the intention of searching broadly on the HIV programme in South Africa and expanding access to ART and scaling-up the programme. We used the following subject headings for the broad PubMed MESH search: (('Health Services' [Mesh]) AND ('HIV

Table 1. Inclusion and exclusion criteria key concept list

Inclusion criteria	<ul style="list-style-type: none"> • Research based in South Africa • Shifts in/increased/expanded ART eligibility • Earlier ART • Immediate ART • Universal ART • Getting more people onto ART • Keeping people on ART • PMTCT and shifts in ART eligibility • PMTCT as an entry point into the ART programme • HIV testing as a strategy to identify PLHIV
Exclusion criteria	<ul style="list-style-type: none"> • Research based outside of South Africa • Studies on pre-exposure prophylaxis, post-exposure prophylaxis, medical male circumcision • Studies not HIV-specific, unless the other condition (e.g. TB, mental health) provides an entry point into HIV care and treatment • Modelling studies

Infections/history' [Mesh] OR 'HIV Infections/mortality' [Mesh] OR 'HIV Infections/nursing' [Mesh] OR 'HIV Infections/organization and administration' [Mesh] OR 'HIV Infections/prevention and control' [Mesh] OR 'HIV Infections/statistics and numerical data' [Mesh] OR 'HIV Infections/therapy' [Mesh] OR 'HIV Infections/transmission' [Mesh]) AND 'South Africa' [Mesh]), limiting our results to the aforementioned date range and to the English language. For the narrow keyword searches, we used the following specific keyword combinations and truncations in the PubMed and EBSCOhost databases, also limiting by date range and language: [(South Africa) AND (HIV) AND (implement*) AND (scale-up) OR 'test and treat' OR 'treatment regardless of CD4 count' OR 'treatment as prevention' OR 'immediate ART' OR 'universal access to ART' OR 'treatment for prevention' OR 'treat all' OR 'early access to ART')].

Second, based on a subjective assessment of relevance, the first author hand searched the reference lists of a sub-sample of 10 key peer-reviewed articles for novel results to include in the review. These articles included systematic reviews and social science articles that used alternative research methodologies. This combination of approaches allowed us to reach a point of saturation in our review, where subsequent searches of the peer-reviewed literature using different keywords rendered results that contained duplicate references and/or irrelevant results.

Screening for inclusion

Our intent in this review process was to have wide inclusivity criteria to provide an overview of the considerations and foci in the peer-reviewed literature as South Africa's ART eligibility criteria have become more inclusive. The first four authors developed a list of concepts (Table 1) to use as a benchmark against which to screen each article's eligibility for inclusion in the review. The 'concept list' includes statements and terms that relate to expanding the number of people on ART through, e.g. 'immediate' or 'earlier' ART, or through HIV testing or PMTCT. Using this list, two reviewers (first and fourth author) read the title and abstract of each result to determine its relevance to our thematic focus. As a first inclusion criteria, we included results that addressed shifts in ART eligibility criteria, including earlier, immediate and/or 'universal' ART or PMTCT.

Following these criteria, we included studies that were about getting more people on treatment or keeping people on treatment. Studies that were about expanding HIV testing in order to get people onto treatment were also included. Finally, we limited our results to studies and opinion pieces that focused on the South African context and that were published in peer-reviewed journals. The two reviewers resolved discrepancies during the screening process in discussion and consultation with the second and third authors.

A consultative process and deductive thematic framework to guide analysis

Our analysis process firstly involved an initial consultative meeting with HIV programme managers and clinicians working in the City of Cape Town and Western Cape Departments of Health. In this initial consultation, we presented an overview of the study types yielded by the database searches, using these to discuss trends in academic publishing on treatment scale-up in South Africa. This consultative meeting with HIV programme managers also helped us to contextualize South Africa's HIV response following release of the 2016 guideline to implement 'universal' access to ART, focusing in particular on how implementation has unfolded in the Western Cape Province (where the managers and clinicians were based).

Secondly, we began charting the screened results, a process that involves synthesizing and interpreting the data by qualitatively sifting and sorting material according to key issues and themes (Arksey and O'Malley, 2005). For our study, we drew on the socio-ecological model, adapted from Kaufman *et al.* (2014), to develop a deductive thematic framework that comprises multiple levels of the health system (see Figure 1). Our definition of 'health system' is informed by work by Sheikh *et al.* (2011, 2014) who understand health systems as inherently relational, and which, in addition to the 'concrete and tangible expressions of health systems' include 'the ideas and interests, values and norms, and affinities and power that guide actions and underpin the relationships among system actors and elements'. As such, in our framework, we distinguish between health systems infrastructure or 'hardware' and the relational aspects of health systems or its 'software' (Sheikh *et al.*, 2011), to allow for the fact that many studies of health systems do not effectively account for the relational. We used this framework as a conceptual and analytic tool to organize the articles into categories based on where in the health system they located the challenge or opportunity for expanding ART access. Our framework should not be understood as declarative, but pragmatic, in that it functions as a mechanism to identify and consider possible trends in what is known about implementing 'universal' access to ART in South Africa and what is perhaps less fully understood or explored; articles could be grouped into more than one category as applicable. These categories included as follows:

- a. The individual or client, e.g. age, sex, gender, socio-economic status, sexual identity, risk perception/behaviour, health-seeking behaviour, mental health, motivations, knowledge and information, personal beliefs, adherence;
- b. The relationship between health worker and client, e.g. relationship power and equity, social support and trust, communication, relationship satisfaction and quality of interaction;
- c. The clinic and/or community context, e.g. the social context of each setting, which includes social and cultural norms and dynamics, organizational culture, social capital, social support and networks, stigma, community organization and mobilization and leadership;

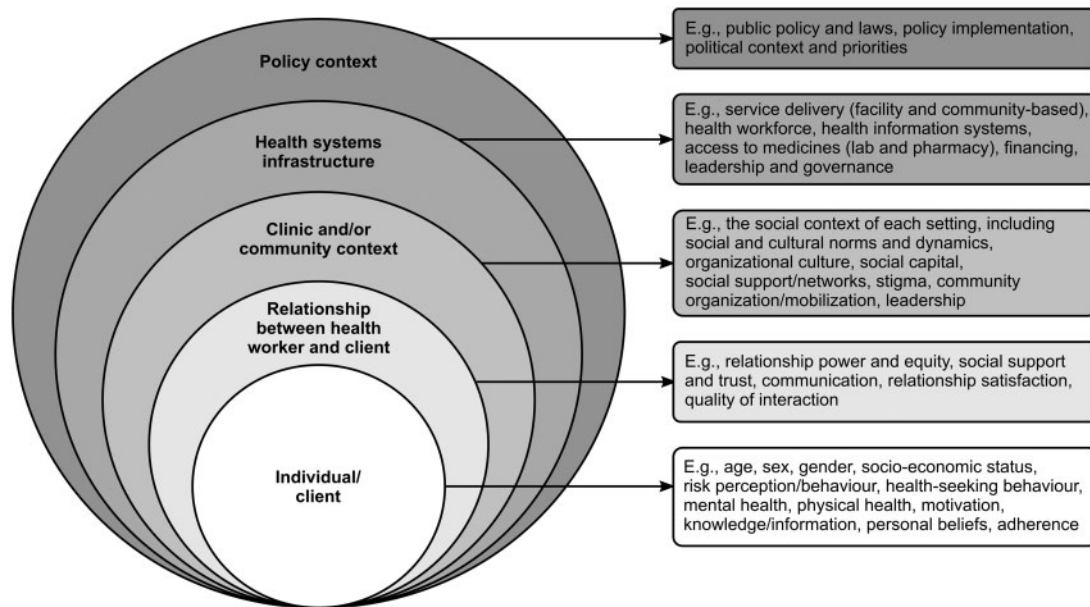


Figure 1. A deductive thematic framework, adapted from the socio-ecological model.

- d. Health systems infrastructure, e.g. service delivery (including facility and community-based), health workforce, health information systems, access to medicines, financing, leadership and governance; and/or
- e. The policy landscape and implementation, e.g. public policy and laws, policy implementation and political context and priorities.

Thematically organizing the results in this way allowed us to map, from the micro-individual to the macro-policy level, the most common challenges and opportunities expressed in the published literature on implementing expanded ART in South Africa, and how these are located across health systems hardware and software. We developed tables, graphs and timelines to analyse and describe the scientific study results and summarized the opinion pieces separately so that we could juxtapose the concerns expressed in the opinion pieces against those of the scientific studies.

Finally, in a second consultative process, we shared these preliminary results in one-on-one conversations (conducted by the first author) with six collaborators, including clinicians and managers working at various levels of the health system. These conversations critically discussed the review results and explored the relationship between the published science and their experiences of the unfolding challenges and opportunities as South Africa implements ‘universal’ access to ART in more detail. This consultative process allowed us to check and refine our findings and to develop the key messages of the paper.

Results

Description of review results

Figure 2 shows the process and outcome of the identification and screening of results included in this review. Our searches across the PubMed and EBSCOhost databases and our manual search across the reference lists of a sub-sample of 10 research articles yielded a

total of 1512 unique results, which included opinion pieces. These are presented in Figure 3 to show the total number of results returned by our database and manual searches per year. The results display an upward trend over time as research on South Africa’s HIV programme increased alongside implementation of policies that have expanded treatment eligibility and coverage. In each year, about a 10th of the overall results were focused on expanded or earlier ART eligibility; others were either not HIV-specific, based outside of South Africa, or included clinically focused HIV studies, mathematical models and studies on HIV risk, peer education and pre-exposure prophylaxis, all of which were excluded for this review.

We then applied our concept list (Table 1) to screen the 1512 results for inclusion. This process led us to identify 194 research articles and 23 opinion pieces that fit our inclusion criteria and which we included in the review. In the below sections, we present our review of the research articles and opinion pieces and share broader insights from the consultative process with HIV programme managers and clinicians and researchers on the PopART trial in the Western Cape Province, South Africa.

We used a deductive thematic framework based on the socio-ecological model described above (Figure 1) to categorize the 194 research articles and 23 opinion pieces according to where the articles located the challenges and opportunities of expanded ART eligibility in South Africa. Supplementary Table 1 shows the coverage of themes for each of the 194 research articles, displayed in chronological order by publication date, with articles grouped into more than one category as applicable. Supplementary Table 2 does the same for the opinion pieces. The predominant challenges and opportunities were concentrated in the individual ($n=89$ articles and opinion pieces) and the health systems infrastructure ($n=152$) categories. Considerably fewer results focused on the relationship between the client and the health worker ($n=14$), the clinic and/or community context ($n=28$) and the policy context ($n=24$). Figure 4 shows the trends in the thematically organized results over time.

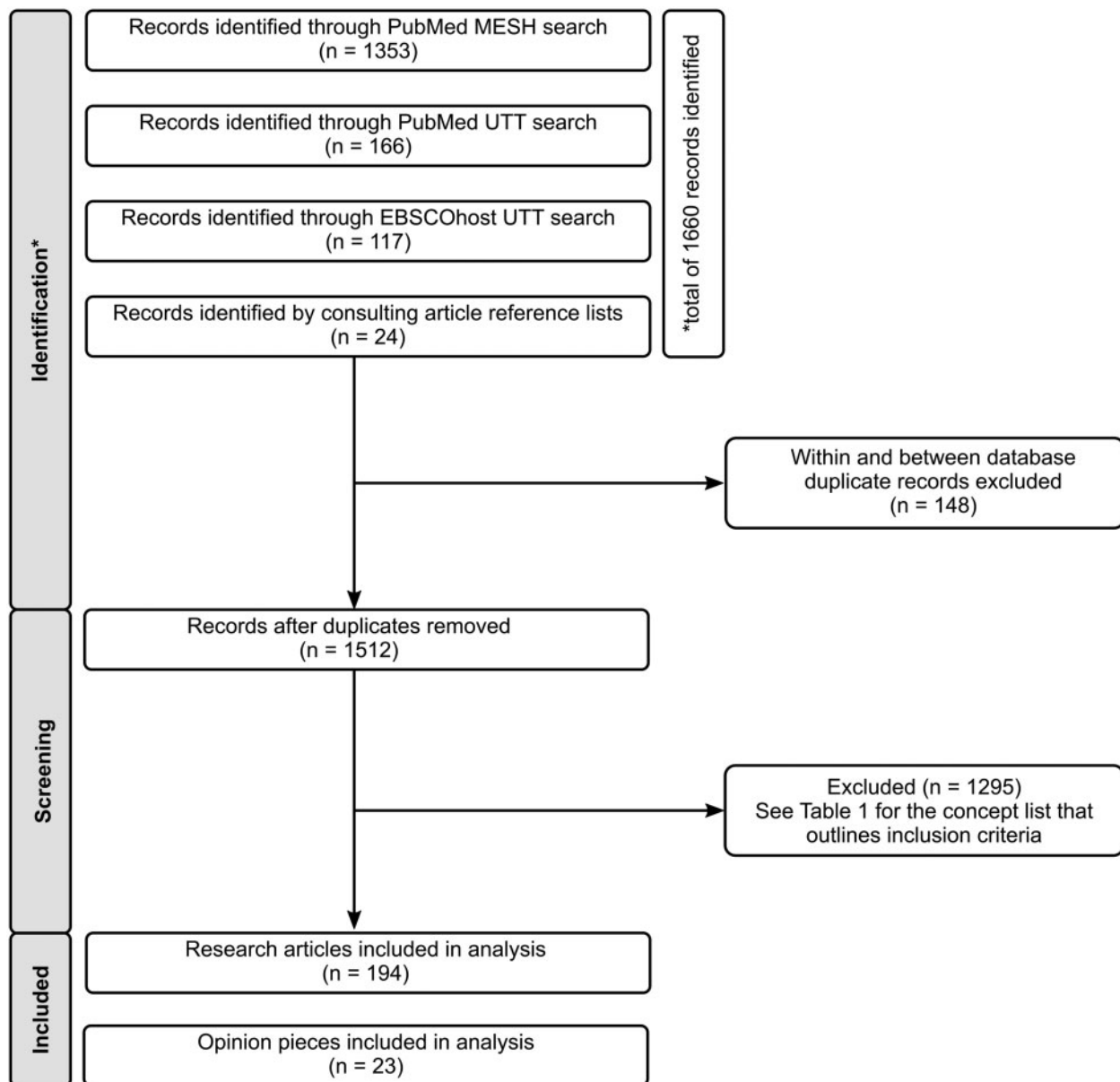


Figure 2. Process and outcome of identification and screening of results.

Individual and health systems infrastructure factors as central focus

In the 'individual' category, published research on scale-up has been steadily increasing over the course of the epidemic. By 2016, half ($n = 81$) of all the peer-reviewed published literature included in the review addressed individual-level factors as challenging or facilitating expanded treatment access. The majority of the studies in this category were focused on quantitative individual-level predictors of HIV testing, linkage to care, retention and viral suppression (the HIV care continuum), as well as risk factors associated with each of these steps rather than qualitatively describing individuals' social worlds. For example, Fomundam *et al.*'s (2017) study found that males, non-pregnant women, individuals older than 30 years and those accessing care in facilities located in townships and inner cities were more likely to present late for HIV care, while Govindasamy

et al.'s (2011) study identified a lower CD4 count, disclosure, symptoms of TB and unemployment as increasing the likelihood that individuals will link to care. A study by Orrell *et al.* (2003) explained that socio-economic status, sex and HIV stage could not predict adherence in developing health settings such as South Africa, and Wang *et al.*'s (2011) study indicated an association between higher loss to follow-up rates and younger age and pregnancy for women. Several studies focused exclusively on women ($n = 8$), including a focus on retention in care of pregnant or post-partum women ($n = 4$). Studies in which men were the sole focus ($n = 6$) explored their engagement with HIV testing ($n = 4$) and 'treatment as prevention' ($n = 2$). Among these was a qualitative study by Orr *et al.* (2017) which focused on men's social context by exploring the ideational and behavioural factors that enable or create obstacles to men's uptake of HIV testing and ART, and a study by Chikovore

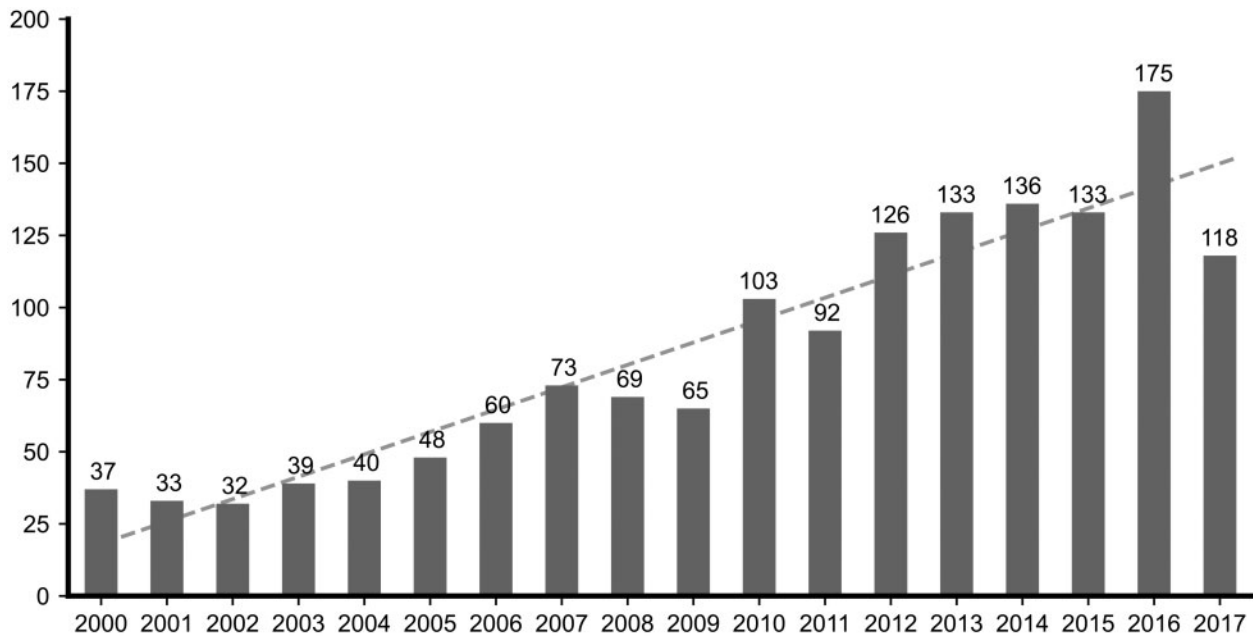


Figure 3. Total number of results returned per year.

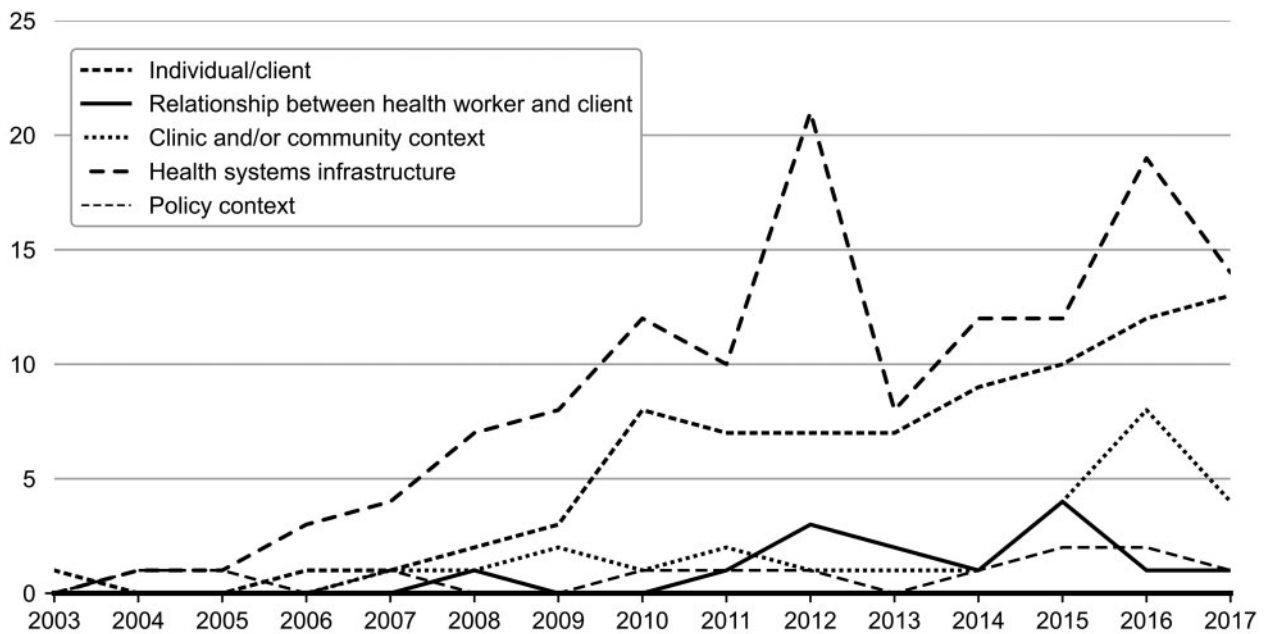


Figure 4. Trends in results over time, thematically organized.

et al. (2016) that similarly examined the influence of masculinity on engagement with HIV care within a UTT context. Many other studies not focused on men also singled out men as a particularly hard to reach group. Thirteen studies focused on children ($n=6$), youth ($n=4$) and adolescents ($n=3$) as categories of individuals that were difficult to reach with expanded HIV testing and treatment. Adherence received significant attention in the literature ($n=12$) as an individual-level factor that influences programme success, or alternatively as a factor that is influenced by other individual-level factors such as depression and substance abuse.

The trend in the ‘health systems infrastructure’ category shows that there has been consistent research interest in factors related to health systems infrastructure that influence HIV programme expansion over time. These research articles address different domains of health system hardware: health service delivery, health workforce, health information systems, access to essential medicines (including laboratory and pharmacy), health systems financing and leadership and governance (WHO 2010). Using these domains, we classified the majority of research articles under the health services delivery and health workforce sub-categories. The studies in the health

services delivery category predominantly included task shifting from doctors to nurses ($n=8$) and called for innovative strategies and models of care to support HIV testing, treatment initiation and retention in care ($n=22$). This sub-category also included studies that identified decentralized services as key to scaling-up the HIV programme. Examples of studies included in this category are Fairall *et al.*'s (2012) study that provides evidence for task shifting from doctors to other health workers in the HIV programme and Duncombe *et al.*'s (2015) study that considers the limitations of clinic-based models to get more people on treatment in a timely manner. The authors propose innovative and differentiated models of care that are tailored to the needs of clients. Additionally, Grimsrud *et al.*'s (2016) study found that clients who initiate ART at higher CD4 counts are at a higher risk of loss to follow-up and called for models of ART delivery that can support long-term retention in care. The study by Mutevedzi *et al.* (2013) similarly identified a higher CD4 cell count at ART initiation as a risk factor for disengaging from care, i.e. becoming lost to follow-up, as well as year of ART initiation—with more years since ART initiation associated with a higher risk for loss to follow-up. The authors suggested that the health system's capacity to cope with an increasing client load might be reflected in the quantitative data and concluded that 'increasing disengagement from care threatens to limit the population impact of expanded antiretroviral coverage' (Mutevedzi *et al.* 2013, p. 934). Some of the models proposed include home-based testing, same-day CD4 count testing, adherence club models and increasing community-based support. Thirty-three studies were categorized in the health workforce sub-category. These studies focused predominantly on health worker shortages, the role of lay and community health workers in supporting the HIV programme and training and skills needs.

Several studies, including the study by Mitchell *et al.* (2012) and Loeliger *et al.* (2016a), discuss the need to formalize and expand the role of non-medical staff such as lay counsellors or community health workers in the face of an expanding HIV programme and limited clinical staff. With regards to implementing 'universal' access to ART, a study by Boyer *et al.* (2016) considers how inadequate human resources could lead staff to prioritize ART initiation in clients with the lowest CD4 counts, undermining the benefits of immediate and early ART. The study by Jacobs *et al.* (2008) similarly considers how limited human and infrastructural resources gave rise to rationing of ART, specifically concerning itself with the equity of the process. A few studies consider gaps in staff skills and training to deliver quality services, such as the study by Kinkel *et al.* (2012) in which they identify considerable variation in how staff adhered to performance standards during consultations and counselling.

Eleven studies dealt with cost and cost-effectiveness in various ways, including Natrass and Geffen's (2005) article in which they consider the cost of providing ART in the public sector vs a prevention only programme, Walensky *et al.* (2011) and Tabana *et al.*'s (2015) studies in which they evaluate the costs associated with different models of HIV testing, Long *et al.*'s (2017) study on the cost and cost-effectiveness of same-day single-visit ART initiation and Hontelez *et al.*'s (2011) study in which they estimated the associated costs of implementing the WHO's (2009) ART guideline recommendation in South Africa. Two studies addressed laboratory and pharmacy challenges, with Steyn *et al.*'s (2009) study discussing how challenges in the national supply chain, shortage of pharmacists and storage for ART caused delays in initiating clients on ART, and Glencross *et al.*'s (2014) study developing a tiered laboratory-based service model that allowed for cost-saving, point of care CD4 count testing to extend national coverage. Four research articles fell into

the health information systems sub-category. For example, a study by Clouse *et al.* (2017) found that, in targeting post-partum women, a unique identifier linked to a national health database is necessary to improve reporting and client care, while studies by Lessells *et al.* (2011) and Cornell *et al.* (2010) identify monitoring as a key area for intervention to maximize retention in care of pre-ART and ART-clients, respectively. A study by Leydon *et al.* (2010) dealt with leadership and governance by way of a data-based calculator to support managers to set targets along the HIV care continuum. Overall, there seemed to be a paucity of literature on the implementation of clinical governance principles in facilities offering HIV and ART care.

Limited focus on health worker–client relationships and clinic- or community-level contextual factors

In contrast to individual and health systems infrastructure factors, the number of studies focused on the relationship between health worker and client and the clinic and/or community context are both limited, but start to appear more steadily in the results from 2009 onwards. In the relationship between clients and health worker category, most research articles ($n=8$) focused on the quality of counselling and/or communication by lay health workers and counsellors who are tasked with supporting adherence in clients as well as their linkage to and retention in care. A study by Knight *et al.* (2015) maintained that 'in-depth counselling creates an "educated consumer" facilitating engagement with clinical services' and a study by Mabuto *et al.* (2017) found that counsellors' ability to collaboratively discuss potential barriers to care could facilitate client engagement. A few of the studies focused on gaps in the skillsets of counsellors, especially with regards to motivational interviewing (Dewing *et al.*, 2013; Fisher *et al.*, 2014) and the psychosocial aspects of counselling (Peltzer *et al.*, 2012). One study (Penn *et al.*, 2011) explored the role of the pharmacist in facilitating adherence in clients, propounding a patient-centred approach to adherence counselling. Five studies addressed the relationship between clients and providers directly, with only one article focusing on a specific health worker type. These included studies by Aspelting and van Wyk (2008) and Watermeyer and Penn (2012) which illustrated the significant impact that a supportive health worker–client relationship can have on adherence, while a study by Smith *et al.* (2013) noted how positive interactions with clinic staff influence retention in pre-ART care. Barry *et al.* (2012) developed a scale to measure the client–provider relationship and found that, in the context of the PMTCT programme, the quality of this relationship affected the decisions that clients made regarding their care. The authors found that clients who did not initiate ART, despite being eligible, scored significantly lower on the client–provider relationship scale. None of the studies in this category addressed power differentials and equity in the relationship between health workers and clients nor the issue of trust. Furthermore, reference to the relationship between clients and nurses, a relationship that is known to be historically fraught, was also markedly absent in the literature.

We found that the research articles included in the clinic and/or community context category were nearly equally concerned with context ($n=6$), community mobilization and engagement ($n=6$), stigma ($n=6$) and community norms and beliefs ($n=8$). In the community context sub-category, authors made arguments for taking 'context' into account in understanding the acceptability of household HIV testing (Naik *et al.*, 2012), or referred to context in terms of the social environment within which community-based adherence programmes were delivered (Masquillier *et al.*, 2015; Masquillier

et al., 2016). Others referenced structural barriers to adherence (Dewing *et al.*, 2015) and the role of social capital in treatment retention (Mukoswa *et al.*, 2017). The article by Ojikutu *et al.* (2007) addressed the role of apartheid, lack of political commitment, poverty and cultural barriers in significantly slowing efforts to provide ‘universal’ treatment access in South Africa. In the community mobilization and engagement sub-category articles focused on how communities may be mobilized to overcome human resource shortages in the health system and for increasing services uptake and linkage to care, e.g. in the form of community health workers (Wouters *et al.*, 2009a; Loeliger *et al.*, 2016b) or community-based support groups and treatment buddies (Wouters *et al.*, 2008; Wouters *et al.*, 2009b; Kemp *et al.*, 2016). There was considerable overlap between the stigma and norms and beliefs categories as many of these studies addressed how stigma resulted from widely held community norms and beliefs. These included gender norms ($n=5$), with a focus on masculinity ($n=2$), and belief in and use of traditional health practitioners ($n=3$). The research that focused on stigma in itself, focused on how stigma compromised the HIV care continuum, with for instance the uptake of repeat testing (Orne-Gliemann *et al.*, 2016), uptake and adherence to treatment (Niehaus, 2014) and retention in care (Smith *et al.*, 2013; Purchase *et al.*, 2016). Our search results yielded no studies on organizational culture or the social and cultural dynamics within clinics and health services.

Results relating to the broader policy context are decidedly low throughout the period reviewed. Studies included in this category are as follows: Snow *et al.*'s (2010) study that calls for sex differentials in HIV testing to receive closer policy attention, Van Rooyen *et al.*'s (2016) study on legal and policy frameworks for testing of children and Loeliger *et al.*'s (2016a) study that maintains that the role of community health workers must be recognized and formally expanded to support the health system.

Opinion pieces: from calling out government inaction to calling for continued advocacy, simplified models of care and self-management strategies

Our searches identified 23 opinion pieces published between 2003 and 2015 to include in the review. The opinion pieces were written by a variety of voices in South Africa's HIV epidemic, including journalists, senior academics, researchers, medical doctors and HIV programme managers and directors. Using the socio-ecological model-based thematic framework, we found that the opinion pieces on treatment scale-up highlighted individual, health systems infrastructure, and policy-related factors as key issues related to expanded treatment eligibility and overall programme success (Supplementary Table 2).

From around 2009, we observed a marked shift with regards to the topics and tone of the opinion pieces. Opinion pieces published prior to 2009 call attention to the South African state and refer to an HIV programme that is generally described as incompetent and/or indifferent, fractious and poorly implemented (Bateman, 2004, 2007; Venter, 2005; Quinlan and Veenstra, 2007; Kapp, 2008; Chikte, 2008). In particular, these opinion pieces focus on government inaction (Bateman, 2004, 2007; Venter, 2005; Kapp, 2008; Chikte, 2008), the repercussions of persistent AIDS denialism (Bateman, 2004, 2007; Kapp, 2008) and gross health system inefficiencies that the HIV epidemic and programme is seen to amplify (Quinlan and Veenstra, 2007).

In the opinion pieces published from 2009 onwards, the overall commitment of the state ceases to be an explicit concern. This aligns with the shift to a newly instituted government cabinet under

leadership of then-President Jacob Zuma and Minister of Health, Dr Aaron Motsoaledi. ‘The Lancet’s’ 5 December 2009 editorial aptly titled, ‘HIV/AIDS: a new South Africa takes responsibility’, epitomizes characterizations of this important shift. The piece notes that ‘this extremely welcome and long-awaited change in attitude, and its appropriate urgency, is accompanied by a burst of behind-the-scene activities at the Department of Health and SANAC (South African National AIDS Council)’, before going on to list a range of strategies that the government will implement, including increasing ART eligibility criterion from a CD4 cell count of 200 to 350 (Lancet, 2009, p. 1867). From here on, the opinion pieces address comparatively more nuanced concerns around the link between HIV research and policy, and the changing role of activism, the individual, community and the health system.

Geffen’s (2009) opinion piece highlights the critical role of activism and science in establishing South Africa’s HIV programme. According to his analysis, the myriad technical issues that hamper the overall programme’s implementation should become the focus of activists, a more complex task than the early advocacy for ART. ‘At a minimum’, he says, ‘activists will need the continued support and assistance of the research community (...) to keep their advocacy effective’ (Geffen, 2009, p. 861). Karim and Karim’s (2010) opinion piece on the link between AIDS research and policy in South Africa highlights the lack of local investment in HIV research, which they argue has resulted in skilled researchers applying their minds to global HIV research priorities rather than research priorities specific to our local context that could more immediately inform HIV policy. The authors maintain that ‘the problem is not a lack of science. (...) What’s missing is an effective conduit between the country’s AIDS research and its prevention and treatment policies and programmes’ (Karim and Karim, 2010, p. 733).

A key consideration that cuts across several of the post-2009 opinion pieces is the monumental task of achieving consistent viral suppression in those who have started on lifelong ART, while also initiating new clients to meet expanding treatment eligibility criteria. As such these opinion pieces focus almost exclusively on chronic disease models for HIV and draw attention to the changing roles of individuals, the community and the health system needed to facilitate their implementation. These include ‘simplified models of care and self-management strategies’ that allow people ‘to take more control over their own treatment and care’ (Bateman, 2015, p. 887). Such care models would be supported by ‘demedicalizing healthy patients’ and ‘promo(ting) self-care’ (Gray *et al.*, 2015, p. 638). Furthermore, authors suggest, adherence clubs, run as ancillaries of health facilities (Bateman, 2013), and mobilization of the ‘underexploited resource’ of community care providers to meet ‘new needs (for social care)’ (Wouters, 2009c, p. 1501) would further support the promotion of self-management among PLHIV. How these strategies would be expressed in national policies and translate into successful implementation remained key concerns throughout these opinion pieces.

‘We are trained in clinical practice but we are not trained in human practice’ – Insights from collaborators

After completing the initial analysis of results applying our framework, we asked collaborators working in the South African HIV care context, including medical doctors and managers working at various levels of the health system, to reflect on the results of the scoping review and to interpret the weight of each category against their own experiences of implementing the HIV programme.

Overall, collaborators supported the published literature's focus on health systems infrastructure as a key factor in HIV programme expansion, explaining that the South African health systems infrastructure has exceeded its capacity and is struggling to support not only HIV service delivery but also other chronic disease programmes. They suggested that there is also significant funding available to conduct research on health systems infrastructure, which may help account for the significant weight of this category in the published literature. One of the collaborators explained that the health systems infrastructure issues that create challenges for HIV programme expansion are general to health programmes, rather than HIV-specific, and require consistent, long-term strategies to address (personal communication, 10 July 2019). They suggested that more integrated approaches are at odds with the focus of HIV donor funding, which favours shorter-term solutions aimed at strengthening the HIV programme in particular. Supporting this point, one of the collaborators identified a lack of literature addressing multiple comorbid diseases (aside from TB and antenatal care) in PLHIV, which is in tension with the increasing prevalence of non-communicable diseases in PLHIV who are on ART and thus living longer. Yet, in many places, HIV services continue to be vertically implemented rather than integrated in the general health service, a shift which would more effectively foster a 'total patient' approach to care for PLHIV.

Despite unequivocally supporting the science and implementation of the national guidelines to offer 'universal' access to ART, in this context, collaborators suggested that the concerted and urgent implementation of strategies to achieve 'universal' access was too ambitious and would overextend grossly overburdened and understaffed health systems infrastructure. While the published research in the health systems infrastructure category proposed community-based models of HIV services delivery as a way to overcome some facility-based health systems infrastructure challenges to implementation, some collaborators expressed scepticism about the resources and readiness of local communities in South Africa to take on the responsibility to implement and maintain such care models without the continued drive and support of health services.

While collaborators located responsibility for the HIV programme's underperformance within the health system's infrastructure, they expressed surprise at the high frequency with which articles fell into the individual category. After reviewing the predominantly quantitative types of studies included in this category, some collaborators explained that the high number of analyses that disaggregate data to the individual level may be due to the availability of routine health services datasets on which such analyses may be performed, rather than individual-level factors being perceived as central to implementation. To a large extent, collaborators stated that they felt that health systems infrastructure hampered individuals' ability to take up and stay on treatment, rather than individuals being to blame for these failures.

A resounding message from all the collaborators concerned the importance of the relationship between clients and health workers and between clients and the health service more generally. Collaborators showed surprise at the dearth of literature on these relationships in the context of scaling-up South Africa's HIV response. One of the collaborators expressed this sentiment by explicitly referring to hardware and software in the health system, noting that despite its limitations, the health systems hardware (referring to infrastructure and clinical care) are in fact operational, while they considered the software (referring to the relational and human aspects of care) to be the dysfunctional element of the system (personal communication, 13 August 2019). Other collaborators shared

similar sentiments in various ways, stressing the importance of this under-researched topic for successful programme expansion:

When we as programme people try and do something around 'universal' test and treat, the thing we're bumping against most is (the relationship between health worker and client). There might be things (issues) sitting in the health system (infrastructure) but if there's something wrong with this relationship, it will undermine all the (efforts) and if there's something extra special about this (relationship) it mitigates all the other (issues) (personal communication, 10 July 2019).

We are trained in clinical practice, but we are not trained in human practice. The one thing that I've learnt is that (for) most of our clients, health is not their priority. Many men have very poor health-seeking behaviour so if he ends up at your service, you're going to have to pull out all the stops. You're going to have to sell the service to him. If his first experience is bad, he's never going to come back. I think that's our problem, we don't know how to have conversations with clients and with the community (personal communication, 13 August 2019).

The underlying need (of clients) is to make a human connection. They (clients) want a human connection and someone who understands their illness (personal communication, 20 June 2019).

Collaborators explained that, in their experience, the lack of literature on health worker–client relationships and the clinic and community context did not reflect their absolute importance for scaling-up access to ART, but may rather be a result of international research and funding priorities. They also acknowledged that the clinic and community context factors, such as the organizational culture in the South African health system and a community's social norms and dynamics, were conceivably more challenging to research and address through intervention, and reasoned that that may also be why these factors are consistently side-lined.

Discussion

This review analysed a total of 194 peer-reviewed research articles and 23 opinion pieces to provide a critical overview of the challenges and opportunities in scaling-up HIV treatment in South Africa and implementing 'universal' access to ART. These results were organized using an adapted socio-ecological thematic framework, showing that they predominantly addressed factors related to the individual and health systems infrastructure in expanded ART eligibility criteria. Opinion pieces focused on changing roles of clients, communities and health service implementers to promote simplified community-based models of care and self-management strategies as South Africa scales-up its ART programme. The sentiments expressed in the opinion pieces were supported by collaborators during our consultative process, who, in the face of severely stifled health systems infrastructure, suggested a move towards researching and intervening in the relational aspects of care and treatment in HIV and primary health care in general, i.e. the health worker–client relationship, and the clinic and community social context. The insights delivered through these three avenues offer an important opportunity to critically reflect on South Africa's HIV response as recorded in literatures and in the personal reflections of people involved in the design and delivery of health services. In this discussion, we first contextualize the predominant focus on individual and health systems infrastructure factors in the published scientific literature on expanding ART access in South Africa. Secondly, we discuss the implications of understanding the challenges around expanding ART eligibility from such a vantage point for shaping the

priorities and implementation of South Africa's HIV response. Thirdly, we reflect on how such a weighted focus may perpetuate certain routes of inquiry into understanding the HIV epidemic in South Africa. Finally, we discuss the strengths and limitations of the data presented in this review.

Contextualizing the predominant focus on individual-level and health system infrastructure factors in the research on expanded access to ART in South Africa

Our review results showed that individual and health system infrastructure factors dominate the literature as key challenges and opportunities in expanding South Africa's ART programme. We provide some context to help understand why these two research priorities are salient in the literature. In the first instance, the literature's focus on the individual-level factors that affect programme expansion and treatment access can be partly explained by the systematic collection and availability of routine health service datasets both for monitoring and evaluation, surveillance and retrospective and prospective analysis. The South African Government has fostered strong collaborations with global HIV programme funders such as PEPFAR and UNAIDS and has established national think tanks for TB, HIV and sexually transmitted infections, all of which encourage use of routine health services datasets for measuring programme performance and for directing the HIV response (SANAC, 2017; PEPFAR, 2020). Disaggregating data by age, gender, key and vulnerable populations, and health conditions/diseases (such as pregnant or post-partum women or TB clients), such analyses and interpretation have been critical in identifying categories of people in South Africa's HIV response that HIV services are failing to reach, or for which quality of care may be inferior and health and treatment outcomes poor. Given the strong local and foreign research collaborations that the South African Government has built over time, the availability of routine health services datasets and the quick turnover of such quantitative analyses to inform HIV policy and response, it is unsurprising that much of the research on expanding ART access in South Africa describes individual-level factors associated with uptake of various HIV services such as testing and treatment and overall health and treatment outcomes. Quantitative performance indicators are often also easier to measure, collect and interpret than qualitative data which are comparatively expensive and time-consuming to collect at scale, context-specific (with perceived limited generalizability) and which, as a result, may be considered of less relevance.

In the second instance, the consistent focus on health systems infrastructure we observed in the literature on expanding access to ART in South Africa may be the result of numerous historical trends in public health management, both globally and locally. Globally, trends in public and global health have favoured vertical, technological solutions to health problems over community-based, participatory models of service design and delivery (Packard, 2016). Locally, South Africa's history of separate development for different racial groups meant that the apartheid government consistently underfunded healthcare infrastructure for the majority non-White population (De Beer, 1986; Andersson and Marks, 1988); public health services were few, hospital-based and curative. Upon South Africa's democratization in 1994, the new country leadership constitutionally enshrined the right to free and quality healthcare and were tasked with realizing this within the remnants of a systematically under-resourced and dysfunctional public health system (Coovadia *et al.*, 2009). Over the next few years, the government introduced a range of reforms that helped to consolidate/centralize

the public health service, and shifted funding from tertiary hospitals to primary healthcare, which became the cornerstone of South African health policy (Gilson and McIntyre, 2007; Van Rensburg and Engelbrecht, 2012; Burger and Christian, 2020). During this time of democratic transition, the HIV epidemic began to establish itself, with a marked rise in HIV infections throughout the 1990s (Simelela and Venter, 2014). A response to the epidemic would ultimately have to be implemented in health systems infrastructure ill-equipped due to decades of disempowerment, discrimination and underdevelopment (Coovadia *et al.*, 2009). AIDS denialism stalled South Africa's HIV response at a critical moment in the epidemic's trajectory (Robins, 2004), causing rates of new HIV infections and HIV-related mortality to increase rapidly (Dorrington *et al.*, 2001). With donor funding support, small-scale pilot studies began to offer ART to PLHIV (using strict eligibility criteria) (Schneider, 2002; WHO, 2003; Naimak, 2006), and following rising AIDS activism and pressure from civil society, South Africa rolled out a national ART programme in 2004 (Robins, 2004; Schneider *et al.*, 2010; Simelela and Venter, 2014). Unsurprisingly then, the capacity of South Africa's health systems infrastructure to successfully provide ART to increasing numbers of PLHIV has been a foremost concern since the programme's start.

As we witness in the research literature, health researchers working in South Africa have focused on identifying shortcomings and areas for intervention in health systems infrastructure, and on trialling and evaluating service delivery approaches and strategies that could facilitate expansion of the ART programme as more and more PLHIV have become eligible for treatment with shifting treatment guidelines, and newly diagnosed PLHIV would need to enter the service. Simply put, researchers have been preoccupied with the hardware of the health system, while the software has been a background factor in ART programme expansion. That being said, this focus on health systems infrastructure has been critical in South Africa establishing the largest ART programme in the world. The question is whether this predominant focus on infrastructure will be sufficient in the long run as the programme continues to expand, requiring innovative strategies to increase the number of clients on ART while sustaining current processes to retain all in care.

What are the implications of a skewed research focus on how we understand the challenges facing South Africa's HIV epidemic response?

The level of research investment and priority that individual and health systems infrastructure factors receive in the published literature on ART scale-up in South Africa offers a limited view of the broader factors influencing the programme's expansion. Such aspect-blindness, we argue, might render other factors that are critical for expanding ART access in South Africa invisible and serve to 'biomedicalize' the HIV response (Kippax and Holt, 2009, p. 1). Our collaborators have shared from their experiences that the relational aspects of care, e.g. the relationship between provider and client, and the clinic/community context are instrumental to achieving 'universal' access to HIV care and treatment, suggesting perhaps that we have come as far as we can with the current service strategies and exhausted health systems infrastructure. Their narratives suggest that multilevel, whole-system approaches to scaling-up to 'universal' access to ART are needed that take both hardware and software into account. Scholars have highlighted the importance of recognizing and understanding health systems as relational, human

systems and the significance of these relationships for successful implementation of interventions and programmes (e.g. Gilson, 2003; Greenhalgh *et al.*, 2004; Damschroder *et al.*, 2009; Sheikh *et al.*, 2014). The opinion pieces included in this review show an overwhelming focus on chronic disease models for HIV care and the need to promote self-care and responsibility among PLHIV (Bateman, 2015; Gray *et al.*, 2015). Similarly, the National Department of Health has called attention to the collective action that is needed from the state and its citizens to test for HIV, to start treatment, and to stay on treatment in order to successfully expand ART access (SANAC, 2017). In all of these examples, community members, PLHIV, communities and the relationships that comprise the health system are identified as resources for amplifying South Africa's HIV response and maximizing programme outcomes. Yet, research on the broader power relations and inequalities that permeate South Africa's health system (e.g. Marks, 1994; McIntyre and Klugman, 2003; Walker and Gilson, 2004; Myburgh, 2013), research on how to foster agency, demand for and responsibility on the part of community members and PLHIV and research on how to intervene on social and cultural norms and dynamics that shape health behaviour, pales in comparison to the research literature that provides evidence for the health systems challenges and individual-level factors that influence ART programme expansion. Moreover, the lack of attention to these factors in the literature gives the impression that only factors related to the individual and to health system infrastructure are critical.

What are the implications of a skewed research focus for South Africa's HIV epidemic response?

These factors' disproportionate under-representation in the research literature on expanding ART access in South Africa arguably mirrors their low perceived importance in the country's response to the HIV epidemic. An over-focus on individual-level and health systems infrastructure factors in the research literature may shape priority areas in policies going forward and funnel further resources and interventions into these areas. Although the relationship between research, policy and practice is still relatively poorly understood, especially in low- and middle-income countries (Poot *et al.*, 2018), some studies suggest that clinical research and research on health systems hardware translates more directly to practice than research on its software. For example, biomedical research may more easily translate into clinical guidelines, an instrumental use, while research on health systems software is more likely to conceptually inform health policy thinking in unspecified ways—a less concrete utility that is difficult to quantify (Weiss, 1979; Edwards *et al.*, 2018). Our review results and consultative process both identified the need for developing and implementing policies that expressly address the software in the system and that include systems of accountability. But, we can only invest in what we understand. Accordingly, research serves to inform funding priorities for more research and intervention. This means that research on these salient factors will continue to attract attention and funding while undercutting investment in research and intervention on the software in the system. If we continue to under-research non-medical modalities to address the epidemic such as how service encounters between health workers and clients are imbued with historical inequalities and power relations, the impact of organizational culture on programme implementation and the community dynamics that shape the beliefs and practices of people who we want to take up services, we will continue to remain in the dark about how these factors impact the epidemic and the programme's performance. More importantly, we will

remain unaware of the potential gains of intervening upon them for South Africa's HIV response.

Review strengths and limitations

The strengths of this review are in its use of a scoping review framework adapted from Arksey and O'Malley (2005), using multiple data sources, i.e. research articles, opinion pieces and a consultative process with collaborators who were among the first to implement 'universal' access to ART in South Africa and the discussion of the contextual history of the South African ART programme. There are several limitations to how far findings from this review can be extrapolated. Firstly, this is a review of the published peer-reviewed literature on scaling-up ART access in South Africa and as such our findings are limited to what has been published. While we include specific opinion pieces authored by journalists, senior academics, researchers, medical doctors and HIV programme managers and directors, our review largely represents the voices of the scientific community through research articles, and of social scientists, clinicians and HIV programme managers who are drawing on their experiences of implementing and researching in the PopART trial and 'universal' access to ART. As such, the review notably excludes the voices of PLHIV, HIV activists, community organizations and civil society more generally. There is scope for another review of grey literature on expanded ART access in South Africa. Secondly, the review uses the scientific literature to gauge the challenges and opportunities of expanded ART access in South Africa, and as such our findings cannot be extrapolated to implementation. Further research is needed to understand how the scientific research foci we evidenced in this analysis inform and shape policy and practice. Thirdly, the Department of Health HIV programme managers, clinicians and PopART researchers who are collaborators in this review are all based in the Western Cape Province, South Africa, which is a uniquely well-resourced province. Because of the PopART trial, this was the first South African setting to implement 'universal' access to ART and as such it provides an opportunity for early exploration. However, it does mean that the perspectives offered by these collaborators cannot be generalized to speak for the experiences and perspectives of those working in South Africa more broadly. Research on this topic should continue as the policy to offer 'universal' access to ART is implemented across the country. Fourthly, our review focuses on how to increase testing and treatment availability to implement expanded ART eligibility criteria, not on the impact of such availability or how to achieve the desired population viral suppression. Further research is needed to review and describe the research available to inform impact. Finally, our review of the published peer-reviewed literature is limited to a predefined set of keywords and to literature focused specifically on the South African context. A broader review of literature from sub-Saharan Africa or globally would have yielded different and important insights. Furthermore, there is certainly other valuable literature that is under-represented in our review due to our focused keyword searches of peer-reviewed publications on South Africa and restricted timelines (e.g. Fassin, 2007; Nguyen, 2007), including relevant historical, sociological and anthropological literature that takes a broader focus than HIV scale-up specifically (e.g. Marks, 1994; Farmer, 1999; Farmer, 2005; Gilson, 2012; Gupta, 2012). There has also been some notable research published after our 2017 cut-off date that focuses on health worker-client relationships, the clinic and community context and policy context. For example, Mukumbang *et al.* (2018, 2019a, 2019b) have published a significant body of work on the

programme theories underlying the ‘adherence club’ intervention, exploring how this intervention mitigates the relationship clients have with the health service and their treatment. Research by Bell *et al.* (2019) explores men’s life context and how both the psychological and practical aspects of this context affects their access to HIV testing and treatment, and a study by Sharer *et al.* (2019) discusses how codification of the 2016 National Adherence Guidelines by health services enabled HIV care that was flexible and which thereby facilitated differentiated, client-centred care.

Conclusion

It has been nearly 40 years since HIV was first discovered, and since then, the HIV epidemic has given rise to unprecedented social mobilization, clinical, biological and social research and global and national investment and effort. While there have been great strides to achieve control of the HIV epidemic globally, each new strategy touted by UNAIDS and other global HIV programmes to ‘end the epidemic’ fails to bring the anticipated returns in many local settings. Perhaps, it is time to consider, as we have attempted to do here for the South African context, the taken-for-granted research and practice pitfalls that could perpetuate limited understandings of the epidemic and our response and blind us to other critical factors that require our understanding and intervention.

In the case example of South Africa, we found that the relationship between health worker and client, and the clinic and community context in which care takes place, is consistently deprioritized in research on HIV, in favour of factors related to the individual and health systems infrastructure. While we do not suggest that the status quo is problematic in itself, or that individual and health systems infrastructure dynamics are not important, the article calls attention to how an overwhelming focus on these factors in the published literature on HIV in South Africa may skew how we approach implementation of expanded ART and keep us from recognizing and addressing other pressing issues that continue to slow implementation. As mentioned earlier in this article, research on health systems software often shapes policy and practice in unspecified ways, which may cause research on such topics to seem less impactful. A focus on individual and health systems infrastructure factors may further minimize research and interventions into avenues that impact on how health workers deliver services, how clients experience and engage with health services and healthcare providers and how broader collectives come to engage with and take up HIV services. Importantly, a focus on individual and health systems infrastructure factors may also keep us from asking the arguably more difficult questions in HIV programme implementation—how to address societal norms and dynamics, how to change health behaviours at the population level, how to build trust into the health system and the relationships that define it, how to strengthen social cohesion and social capital in communities and how to positively impact stigma—and thereby delay our progress towards achieving HIV epidemic control.

A more complete understanding of the challenges and opportunities facing HIV programme implementation can only be achieved by fostering genuinely multidisciplinary approaches to researching these phenomena. HIV is by its very nature a social disease, with transmission taking place in the most intimate aspects of human life and management of treatment requiring lifelong relationships with health services. Including critical perspectives on the relationships that make up health systems and services—between clients and providers, community members and individuals—is essential to understanding the complex challenges to and opportunities for achieving ‘universal’ ART access in diverse contexts.

Funding

Funding for open access publication was provided by the University of Amsterdam.

Acknowledgements

We would like to thank authors and collaborators from the Desmond Tutu TB Centre’s Social Behavioural Sciences team, the HPTN 071 (PopART) trial and City of Cape Town and Western Cape Provincial Departments of Health for their interest, time and support.

Author contributions

H.M., G.H. and L.R. contributed to study conception and design. H.M. and D.v.A conducted the literature review and initial data analysis. H.M. prepared the first draft of the manuscript with input from G.H. and L.R. All authors contributed to data analysis and interpretation and critically revised the draft. All approved the final version submitted.

Supplementary data

Supplementary data are available at *Health Policy and Planning* online.

Conflict of interest statement. None declared.

Ethical approval. Approval was provided by the Health Research Ethics Committee of the University of Stellenbosch, South Africa.

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