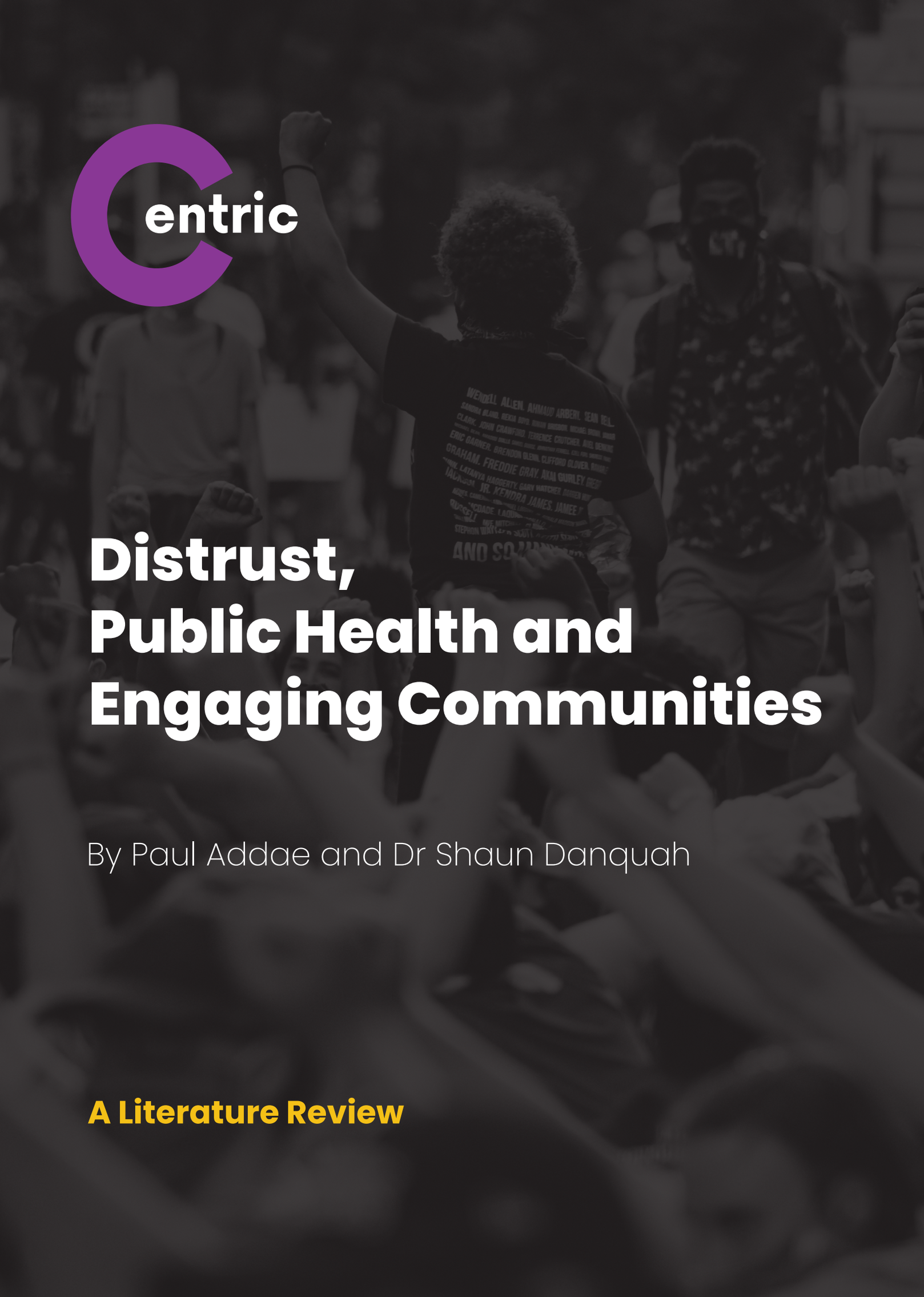

Centric

Distrust, Public Health and Engaging Communities

By Paul Addae and Dr Shaun Danquah

A Literature Review

About the authors

Paul Addae (BA, MA) is a graduate of The School of Oriental and African Studies. He has conducted research over the last 15 years in some of the most challenging and volatile environments. He has co-produced research with professors from Georgetown University, Exeter University and St Andrews University. He has also worked on EU projects around effective solutions to some social phenomena. Paul is also a fluent classical Arabic speaker and has translated many works into English.

Dr Shaun Danquah (BA, MA) is the founder and Director of Innovation at Centric. He has 15 years' experience in conducting research across hostile environments. This began in 2004 with his involvement in founding the Clapham Park Project, which was part of a £56 million regeneration scheme. He also worked on government programmes and on Los Angeles gang intervention initiatives, delivering workshops on best practice. His work led him to partner with Google, Ideo and YouTube. As a result of his work, he has successfully established networks across various underserved communities.

Paul and Shaun have worked jointly over the last 15 years on different research assignments in the US and UK.

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Introduction

Individuals have a stake in healthy communities which support and bolster their wellbeing, an unhealthy environment on the contrary may promote harms such as ill mental and physical health, crime, violence, poor social relations and environmental risks. In this way, the social capital (comprising the norms, networks and institutions of communities) are a key determinant of health for people and communities (Putnam, 1995, 2000). There are therefore diverse psycho-social dynamics which impact the adoption of positive health behaviours.

However, barriers to participation include distrust of health promotion messages. As distrust may impact communities who are the most marginalised there has to be strategies and approaches which take this into consideration and aim to alleviate this. In 1990 Fink and Shapiro found that some women refused to participate in breast cancer screening programs. Reluctant participants were engaged via intensive culturally-nuanced outreach and personal contact at a variety of locations which were frequented by women.

Why This Literature Review Approach?

Centric has found over the last eighteen months that it is important to coalesce theoretical nuances which are largely confined to academic literature with community insights.

The first literature review Centric conducted on community research formulated by Centric provided the theoretical framework for the Centric ethos. This meant that Centric's research practice was informed by fresh theoretical approaches which had been hitherto confined to academia and literature.

The first literature review allowed us to deep dive into nuances regarding conducting research in communities and health, and the relevant concepts and approaches, such as 'research extraction', 'parachute models' and the 'inbetweener' approach to formulate best practice which informed Centric's community research model at the initiation of the medical scepticism scope of work.

What we hope to do is build Centric workshops around the themes which have been identified here, for statutory staff members and community researchers. This literature review is the first port of call to foster critical dialogue around rebuilding trust, as an accessible template can subsequently be developed.

Local Authorities and Public Health Community Engagement

Community engagement is emergent as a key facet in the implementation and development of public health interventions. Moreover, in emergency situations such as pandemics, there is a greater need for local authorities to develop communication in ways which maximise positive behavioural responses from populations (Thompson et al., 2022: 1035). Community members can take on roles including participation in consultation processes, collaboration or leading in the design, delivery and evaluation of public health strategies. A report in 2009 by Herbertson et al articulated the following checklist for effective community engagement:

1. Prepare communities before engaging
2. Determine the level of engagement required
3. Integrate community engagement in each phase of the project
4. Include traditionally excluded stakeholders
5. Gain prior free and informed consent
6. Resolve community grievances through dialogue
7. Promote participatory monitoring by local communities

With engagement, it is important to avoid a myriad of pitfalls however which have been highlighted by Birley (2011: 139). Firstly, promises which cannot be kept should not be made. Secondly, care should be taken to avoid biases. Thirdly, all groups should be represented. Fourthly, medical professional should be part of any engagement.

Community engagement is ideally situated for disadvantaged and socially deprived groups, this is relevant for London conurbations such as Southwark. Innovative community engagement promotes social justice by giving a platform for those usually unheard in society to have a voice and be a part of developing interventions which can better meet the needs of communities. In this way, culturally competent and empathic approaches are facilitated. O'Mara-Eves et al (2015) argue that community engagement in public health interventions has an impact on several health outcomes including health behaviours and self-efficacy.

However, Abuelezam (2021: 159) has discussed how 'engagement' in public health has often missed the target and that within public health are a plethora of examples of unethical community engagement.

Birley (2011: 140) states that:

Effective engagement means involving the local community in the actual decision-making process. Proponents are naturally hesitant to do this and may seek to reduce the level of engagement to a minimum. For example, engagement may become a one-way communication of information.

This is short-sighted and can engender community distrust. Engagement should be built on the principle of free, prior and informed consent. Many plans have failed because of community mistrust.

Local residents therefore should have their perspectives acknowledged, the scope of public health interventions reorientated where necessary and their ideas documented to inform the future implementation of public health proposals. Having a multifaceted approach to engagement, wherein the most marginalised and offstage segments are involved, enables the development of strong relationships and thereby valuable public health strategies.

Community engagement in public health is particularly important as:

- Members of the local community can offer new perspectives on how local authorities can promote health.
- Enhances communication among stakeholders which can lead to better collaboration and understanding.
- The social determinants of health in the locale are a recognised ethical obligation of public health professionals and can be directly addressed in more relevant ways.
- The involvement of local communities can improve the impact and sustainability of health initiatives.
- Resources can be better allocated in tandem with local community health needs

Local Authorities and Public Health

Local authorities can often damage relationships with sections of their communities if there is a sense that there is no avenue for consultation, little recourse for feedback and when there is a general feeling that locals are being held in contempt in lieu of the ideas of 'experts'.

Deferring to expertise thinking is of course always necessary but it should have an equal seat around the table alongside local community knowledge and lived experience to ensure that there is not an imbalance of power. This is even more significant when it comes to health-related interventions, behaviour change and public health strategy. The lack of local community knowledge can in some instances reinforce the current crisis of epistemic trust (Goldenberg, 2021).

An example of this more recently, and closer to home, is with the tension which has arisen because of the Low-Traffic Neighbourhoods (LTNs). Southwark Council launched their Streetspace programme to enable more walking and cycling while public transportation was reduced.

These measures coincided with both the Mayor's and the council's plans to reduce car use and increase healthy active travel. Yet campaigners locally have suggested that the Dulwich Village trial cannot be an effective LTN due to not eliminating some through routes. Southwark Council between 11th January and 28th February 2021 issued more than 22,400 fines to people driving through Dulwich Village LTN and 29,530 penalty charge notices issued to motorists driving through Braganza Street in Walworth. The revenue accrued for the council is said to have been at over £2.5 million, and this was from four LTN cameras in Dulwich and Walworth. The LTNs in Dulwich therefore have caused controversy, apathy and distrust in Southwark.

This current crisis of trust is also a challenge facing public health as they too succumb to the wider societal trend of distrust of government (Hardin, 2004), politics (Claude and Hawkes, 2020), science and media (Birkhead et al., 2022: 269; Warner and Lightfoot, 2014: 452; Stoto et al., 1996: 11). Also narratives of distrust towards government have roots in the liberal political theory of Hume, Madison and Locke as distrust and cynicism towards governments was deemed to be the default setting of the thinking citizen. The notion of 'liberal distrust' (Hardin, 2004: 4).

This distrust is not merely on account of the 'scientific expertise of a particular country not being recognised', which was suggested by Meyer (2016: 449). As where there is a lack of trust in government, there will also be a lack of trust in local authorities and associated government-supported public health initiatives, this has been seen in parts of West Africa where civil wars and violence led to a lack of trust in government institutions (Richardson, 2020: 53). Fisher and Salmon (2014: 435) noted that in Liberia during the Ebola epidemic this was the reason to people being reluctant "to accept contact tracing, movement restrictions and attempted quarantine."

Hence, the onus is also upon medical institutions to also be aware of distrust, cynicism and scepticism that they may encounter when out in the communities and in the field (Cohen, 1991; Mays and Jackson, 1991 and El-Sadr and Capps, 1992).

Moreover, contrary to Meyer (2016: 449), Richardson (2020: 5) suggests that there is an "epidemic" of coloniality of knowledge production within "the mechanisms in public health science- in particular, epidemiology- that enable groups to sanction one account of disease causation over another".

There are credible reasons which have been noted by Washington (2007), who notes:
The lingering effects of unethical medical experimentation on black people has reverberated in the collective consciousness of the black diaspora in America, Europe and on the African continent itself, thereby impacting distrust. This, and other historical evidence of medical malpractice and bad faith research has been enough for the Black diaspora to be quite apprehensive of medical institutions, healthcare services and clinical trials. Hodge (2022: 78) states:

The effect of the Study has had negative public health ramifications far beyond what was anticipated.

Public health ethics therefore has to respect community values and roles, uphold social justice and seek health equity for groups experiencing health disparities.

Communities and Distrust of Public Health

Deep-seated mistrust in public health and medical institutions among black communities has been prevalent for over 50 years (Brandt, 1978; Olson et al., 1988; Hall et al., 1991; Jones, 1991; Thomas and Quinn, 1991, 1993; Phillips, 1993; Reitz and Callender, 1993; Nickerson et al., 1994; Blendon et al., 1995; Mouton et al., 1997; Gamble, 1997; Blanchard, 1999; Corbie-Smith et al., 1999; Bushy, 2000: 148; Lillie-Blanton et al, 2000; Finnegan et al., 2000; Freimuth et al., 2001; Corbie-Smith et al., 2003; LaVeist, 2005; McCallum et al., 2006; Randall, 2006; Washington, 2006; Jamison et al., 2019).

In 1984, fifty-two thousand African-American women were screened for sickle-cell anaemia and over a quarter of them were screened without their knowledge or consent, and as a result neither received the potential benefits of the screening nor gained any education or guidance regarding the condition (Dula et al., 1993: 187). This was all alongside sterilization, and the medical system's role in exacerbating inequalities along the lines of race (Randall, 2006: 199).

Hence, Thomas and Quinn have discussed (1993) for many black communities there is the notion that public health agencies conspire to commit genocide against them.

In 1988, Olson et al. had noted that distrust of health professionals may limit the outreach of public health organisations which do not collaborate with trusted community institutions.

Gamble (1997) also notes that mistrust goes beyond Tuskegee and is also rooted in racial inequalities in medical decision-making. Hence, the distrust of medical professionals which has been replete among black communities necessitates that these communities will prefer to turn to other members of the communities for advice on health, medication and wellbeing (Guadagnoio et al., 2009; Jacobs et al., 2006). This is a core reason for the prominence of counter-public health spheres within such locales. Ball and Strekalova (2020: 219) also noted that deficiencies in the delivery of mental health services within black communities can also instil medical mistrust.

Misdiagnoses are less likely to occur, and communication is more efficient when there is cultural representation in the profession along with a comprehension of the cultural context of the patient. This has been found in research in the US by Whaley (2001) and also Sue et al. (1991).

Mistrust of government institutions exists in many grassroots communities such as indigenous communities wherein there was a history of deliberate infection or of inferior healthcare (Vernon, 2001, 8), or the sterilization of Native American women in the 1970s (Bubar and Vernon, 2009: 32) and as a result of this there is the "historical legacy of causing Aboriginal mistrust of mainstream service providers" (Taylor and Thompson, 2011: 302).

This creates distrust and wider suspicion of health care services (Kunitz, 2015: 181) and such distrust prevents seeking diagnoses, medical assistance and healthcare. There can often be widespread community distrust of government institutions responsible for ensuring public health in situations wherein there is high levels of environmental insecurity (Prasad, 2003: 263).

There is distrust of traditional means of addressing public health issues; and for some time public health authorities and officials took for granted levels of public compliance (de Waal, 2021) and hence the old adage of "trust me, I'm a doctor" will no longer wash.

De Waal states:

> Minorities and formerly colonized peoples have had good reasons to distrust the official health apparatus, which too often treated them with contempt.

De Waal also stated that Western publics are growing suspicious of medical authorities (De Waal, 2021). Greenberg et al. (2015: 82) concede that the "legacy of distrust that exists between minority populations and the medical community is an undeniable consequence of historical experimentation on certain groups." Mistrust and fear of healthcare systems can lead to barriers in accessing services and care thereby exacerbating health disparities. Yet there can also be distrust on the part of public health officials of politicians when it comes to population health (Gostin and Stone, 2007: 66).

However, there is an intergenerational element here as older generations, such as those who arrived during Windrush, appear to be more trusting of institutions. Previous research conducted by Centric has revealed a sentiment among older participants that there were overall quite trusting of their healthcare services.

Rebuilding Trust

Heller and Wyman (259-260) note that any efforts to promote community change are increased when the beneficiaries and recipients of the project trust and respect the people who are actively involved in promoting any new behaviours. Hence, community workers who have a rapport with people in communities can facilitate health communication and behaviour change.nWhere communication is lacking this is often a cause of community distrust (Beaton, 2006: 54). Alelezam (2021: 160) notes that public health professionals and clinicians should aim to take
responsibility for past actions, make amends, and regain trust within these communities.

It is essential that public health professionals work with communities to assess their needs and desires with regard to health. Working closely with communities to understand and right past harms may help to improve relationships with communities in the future. Dismantling systems of oppression in society will go hand in hand with community engagement. Additionally, ensuring that healthcare professionals and public health researchers are trained in inclusive and anti-racist practices will ensure a more appropriate workforce that is attuned to the needs of individual communities.

Alelezam also highlights the significance of forms of community research to better engage communities in productive ways and particularly when it comes to issues around public health. Buchanan (2019: 345) suggested that communities should also play a role in deciding on policies which impact them particularly where there are higher potentials for harm.

Indeed, threats to public health, and to climate change for instance, have major adverse effects on the most vulnerable communities. Buchanan has highlighted (2008: 15-21) that increased autonomy for communities results in better health and hence when communities are empowered to take care of themselves and those around them this a more just process rather than paternalistic dictates issued from distant authorities. Hence, there must be a clear communication strategy where affected communities are involved.

Saunders et al. (2013: 156) state:

> It is not enough to simply make information available for use by the public. When conducting investigations, involving the community must be an integral part of the process and should be planned for.

An example of this with the LTN issue alluded to earlier, is that Southwark Council has been more proactive in engaging residents as in April it launched an eight-week review of the Dulwich LTN and gathered the views of residents. Moreover, Southwark Council also used other measures such as online meetings in May and June 2021, reviews of previous feedback, analysed of motor vehicle metrics before and after the LTNs, assessed bicycle and pedestrian movements and monitored air quality and local congestion. In April 2021 Southwark Council also announced exemptions for blue badge holders who live in Dulwich and Walworth LTN trial areas.
Southwark Council also made changes to Great Suffolk Street LTN in March due to the impact on journey times and after discussions with local councillors and emergency services. The key here is that Southwark communicated with local communities and stakeholders over the issue, the same also needs to occur when it comes to public health and wellbeing of residents within Southwark.

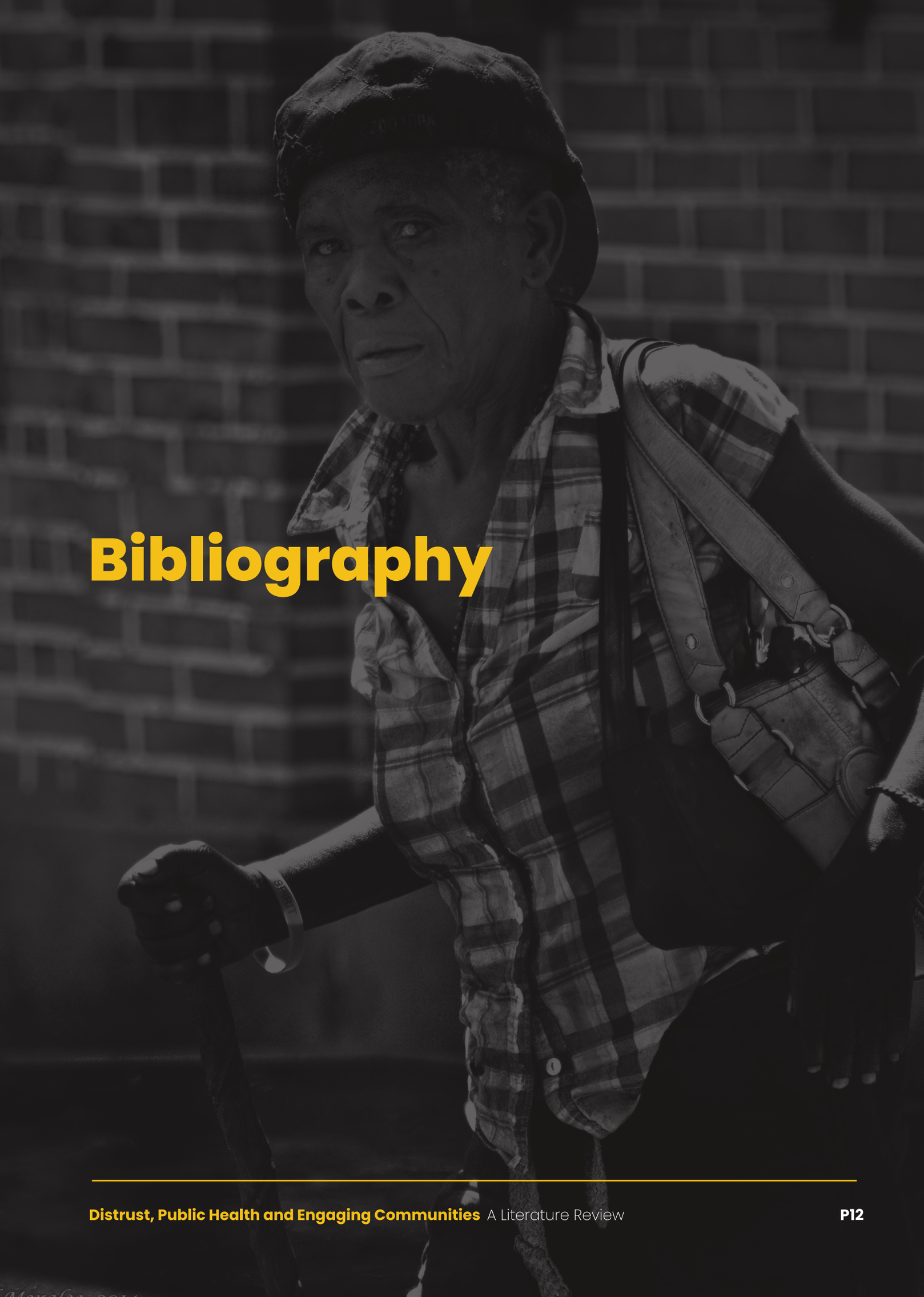
Recommendations

Rules must be developed which provide a framework which inspires action and provide a guide to promoting dialogue with communities to co-design local solutions apt for the urban locale and tackle the lived reality of distrust. Local authorities therefore must think creatively and realise that it is not about convincing communities to trust them, but rather about showing communities that they are deserving of being trusted. Centric has developed the 7 Rules for Rebuilding Trust as a framework to facilitate the trust rebuilding process.

Many communities feel that are limited opportunities for engagement with their concerns and that there is inadequate recourse to be involved in decision-making and designing interventions.

Centric's experience and expertise in direct public and community engagement can assist local authorities to review the way they engage with local communities in the city and re-design service outputs where necessary.

Given the complexities of the issues at hand, it is vital that there is open innovation with entities which sit outside of the traditional public health space and have the autonomy and independence to utilise their links with communities to inform fresh new initiatives and interventions. Centric can play a key role here in a climate of institutional disconnect and also play a cultural mediative role with local authorities in a spirit of transparency and discussing insights via an urban brokerage approach.



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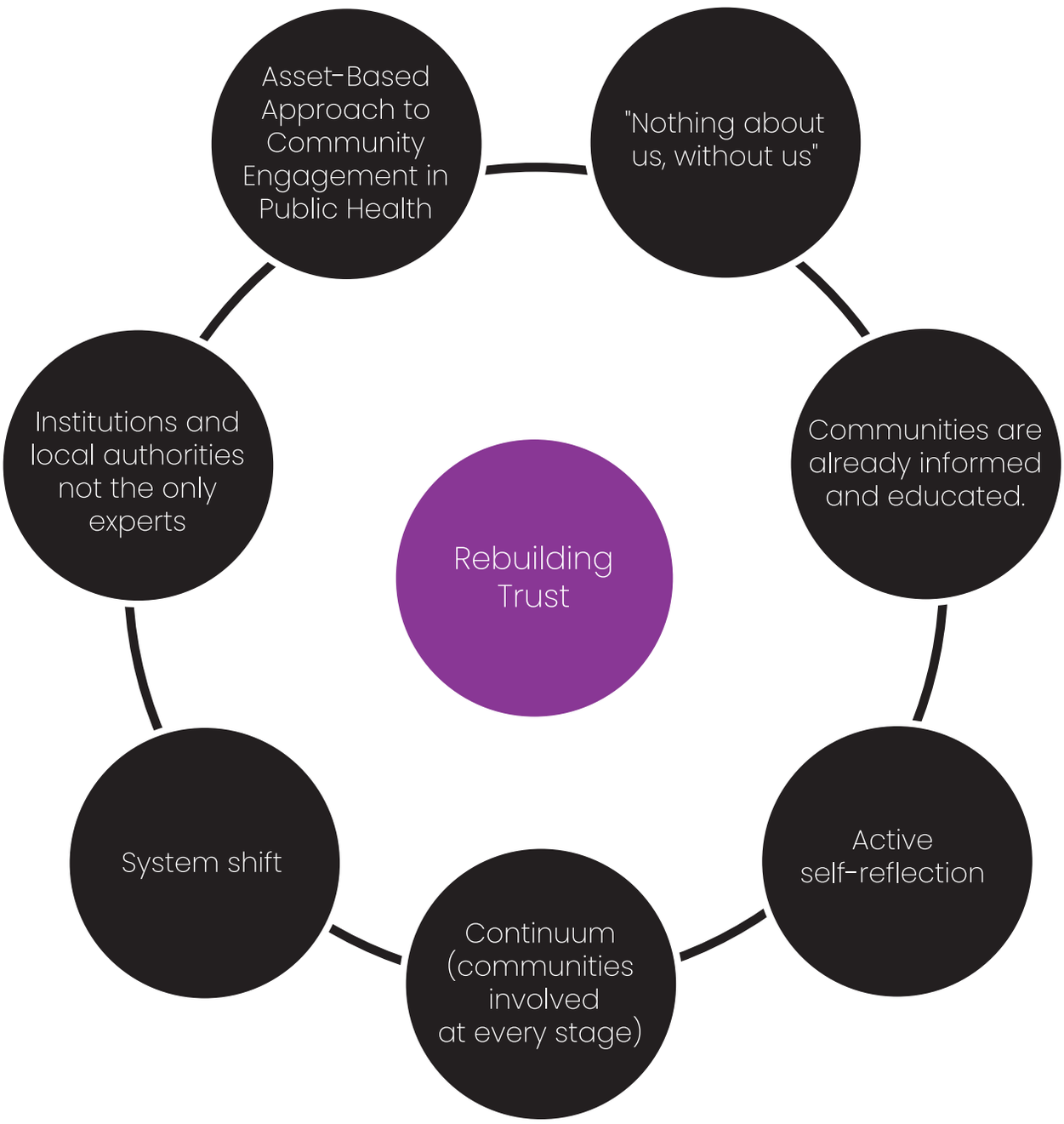
Appendix 1

‘7 Rules for Rebuilding Trust‘



The Seven Rules for Rebuilding Trust

Rule no.1: "Nothing about us without us"

- true inclusion of communities in public health
- co-production of health solutions apt for the locale
- ensure authentic co-design and co-delivery
- Do communities have an equal seat around the table in a truly equitable and democratic format?
- Is polarising language used with the community?

Promotes: effective inclusion

Rule no.2: Communities are already informed and educated

- Contrary to deficit-based approaches when interacting with communities; assuming that communities are entrenched in "health illiteracy"; or approaching communities from the perspective of 'informing' rather than listening or involving communities.
- Strengthens relationship between local authority and communities as both knowledge and power are equilibrated.
- There are a range of issues which are occurring offstage unbeknown to institutions and local authorities
- Centric's team comprises community interlocuters equipped with accessibility, credibility and positionality (ACP) are well-placed to coordinate with local authorities in regards to these insights.
- Insights which are often under the radar can be detected

Encourages: meaningful dialogue, respect and responsibility

Rule no.3: Active self-reflection

- All around the table recognise their own preconceived notions.
- Preconceptions held by local authority can be transcended in order to collaborate with communities to produce knowledge, strategies and approaches shared by all.
- Local authority actively reflects on their motivations and on power disparities between them and communities as a means of both learning and improving community engagement.

Facilitates: true collaborative actions and humility.

Rule no.4: Continuum

- Communities are involved at every stage of the engagement processes
- Increases local capacity to address health issues pertinent to their locale
- Communities have a stake in decision-making
- Evaluation and dissemination public health plans should be built into partnerships with communities
- How is the local authority engaging with the community?

Promotes: maintaining relationship between local authority and communities

Rule no.5: System shift

- Realising that fresh new approaches are required to engage communities as key partners.
- Investing in relationships wherein communities play an active role in their own self-determined health agenda.
- Facilitating safe spaces for an equitable exchange between communities and local authorities, wherein new ideas and co-produced strategies for public health can be discussed.

Rule no.6: Institutions and local authorities are not the only experts

- Institutions and local authorities should listen rather than approach communities from a dominant positionality.
- Deferring absolute insight and expertise of local circumstances away from dominant institutions and local authorities.
- Institutions and local authorities to be prepared to be uncomfortable but also be transparent and open about promises.
- Do local authorities in their ways of working reinforce an 'us versus them' schema?

Facilitates: humility and self-awareness

Rule no.7: Asset-based approach to community engagement in public health

- Ensuring communities have adequate access to a broad range of integrated and holistic health interventions and options within South London.
- Forging partnerships with communities to co-design and co-produce strategies to reduce health inequalities.
- Engagement with those most at risk of poor health in already marginalized and disadvantaged communities within South London.
- The creation of connected, cohesive and resilient communities.
- Taking action on the social determinants of health and wellbeing.
- Utilization of salutogenic notions to identify the factors that promote human health and wellbeing and prevent stress in the city.
- Increase local authority staff confidence to address public health issues with communities.

Embeds: *holistic approaches to healthcare provision in South London boroughs by emphasizing social prescribing, and improves access to social sources of support and community services*

Centric

Thankyou

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