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Vaccine hesitancy, refusal and access barriers: The need for clarity in terminology

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ABSTRACT

Although vaccination uptake is high in most countries, pockets of sub-optimal coverage remain posing a threat to individual and population immunity. Increasingly, the term 'vaccine hesitancy' is being used by experts and commentators to explain sub-optimal vaccination coverage. We contend that using this term to explain all partial or non-immunisation risks generating solutions that are a poor match for the problem in a particular community or population. We propose more precision in the term 'vaccine hesitancy' is needed particularly since much under-vaccination arises from factors related to access or pragmatics. Only with clear terminology can we begin to understand where the problem lies, measure it accurately and develop appropriate interventions. This will ensure that our interventions have the best chance of success to make vaccines available to those who want them and in helping those who are uncertain about their vaccination decision.

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In most countries, although uptake of childhood vaccines is generally high, pockets of under-vaccination pose a continued threat to individual protection and population immunity, with some of these pockets the foci of recent disease outbreaks [1,2]. Vaccination safety scares have led to long-term reductions in coverage, as evidenced by reduced coverage of MMR vaccine in many countries post the suggested association with autism [3,4]. Increasingly, experts and commentators have used the term 'vaccine hesitancy' to explain sub-optimal vaccination coverage [5].

However, we contend that the current accepted definition of 'vaccine hesitancy' to explain all partial or non-vaccination is inaccurate, and risks generating solutions that are a poor match for the problem in a particular community or population. Here, we propose more precision in the use of the term 'vaccine hesitancy,' and its delineation from factors related to access and pragmatics. Only with a clear distinction between these determinants can we develop appropriate policies and strategies targeted to the specific drivers of under vaccination in each population.

Hesitancy is defined in the Oxford English Dictionary as "The quality or condition of hesitating; indecision, vacillation; an instance of this." To hesitate is to "hold back in doubt or indecision; to show, or speak with, indecision; to find difficulty in deciding; to scruple." These definitions portray hesitancy as a psychological state which may delay action or result in inaction. The terms "hesitant, hesitate or hesitancy" were first applied to vaccination in 1994 to describe physicians' reluctance to prescribe a vaccine. From 2004, journal articles began to relate hesitancy to parents or adult vaccination recipients, reaching a peak in 2015 with 50 articles indexed in Medline using the term.

The term "hesitancy" is now widely used in public commentary about vaccination coverage, with three problematic patterns emerging: (1) 'Vaccine hesitancy' is represented as a behaviour, even though it is a psychological state; (2) the label 'hesitancy' is applied to non-vaccination broadly, when in fact some non-vaccinators are forthright in their refusal, and may never have been hesitant and (3) 'hesitancy' is used inaccurately as the explanation for under-vaccination in a population when the causes are related to pragmatics, competing priorities, access, or the failure of services or policies.

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The WHO SAGE vaccine hesitancy working group (which was constituted to address the emerging phenomenon in November 2011) grappled with defining vaccine hesitancy. It rested with a behaviourally-related definition: “a delay in acceptance or refusal of vaccines despite availability of vaccination services”. The group rightly noted that hesitancy is a complex and context specific phenomenon, varying across time, place and vaccines. However, its report went on to conclude that vaccine hesitancy is influenced by factors such as confidence (do not trust vaccine or provider), complacency (do not perceive a need for a vaccine, do not value vaccination), and *convenience* (*access to vaccines*) [5]. The working group defined *convenience* as the extent to which factors including physical availability, geographical accessibility, and the ability to understand because of issues with language or health literacy, affect uptake. It suggested that elements of the service such as its quality (real or perceived), delivery and cultural appropriateness could affect the decision to be vaccinated and thus lead to vaccine hesitancy. We consider these to be physical barriers to vaccination, rather than a psychological state. Puzzlingly, the working group excluded factors such as lack of a vaccine offer, difficulty accessing immunisation clinics due to long distances, and lack of communication about vaccine programmes from the definition of vaccine hesitancy, instead describing them as ‘system failures.’ We agree with this categorisation, but reflect that according to the working group’s definition of hesitancy, these system failures might also have been classed as *convenience* issues. Finally, there is also the acknowledgement by the working group that while some parents might still value and have access to vaccines, vaccination may be a low priority for them due to domestic pressures or busy lives. The working group included this type of situation, which is clearly related to convenience and access issues, within the realm of vaccine hesitancy.

We believe that adding the concept of ‘convenience’ (and its related notion of parental prioritisation) to a definition of hesitancy is problematic, and the problem is compounded by the imprecision in the definition of convenience used. It bundles together concepts relating to individuals’ decisions (selecting out or refusing vaccines) with individual and system-level factors that may contribute to difficulties accessing vaccines. Understandably, the WHO report sought to keep service-related factors on the global agenda, ensuring that countries and services continued to be accountable for their role in ensuring high vaccination uptake. However, the settled definition perpetuates terminological imprecision; indeed Dube [6] reported inconsistencies in the interpretation of the terminology by European immunisation managers. This imprecision could lead to the development of solutions, policies and interventions designed to overcome ‘vaccine hesitancy’ that fail to account for the range of causes of sub-optimal vaccination.

Notably, the problematic usage of the term ‘vaccine hesitancy’ in the media and medical literature does not give sufficient emphasis to the social determinants of vaccination. Many studies have found access barriers to be a significant reason for children not being up to date with their vaccinations [7–9]. These children are more likely to be economically disadvantaged, belong to larger families, and face practical or logistical challenges to access [8–10]. We acknowledge that these are population risk factors for low uptake, and that lack of access may not be the only reason for low uptake in disadvantaged groups; low vaccine confidence may also play a part, underlining the importance of understanding the cause of low vaccine uptake in communities and groups [11].

However, access barriers at both an individual and a “system” level (such as lack of transport or money) are ripe for solutions to minimise them by providing accessible, responsive services. Interventions such as hospital-based opportunistic immunisation [12], domiciliary immunisation [13], following up and reminding parents [14] about due immunisations or facilitating time off work

for parents are effective, and continue to be important in improving coverage. Here, governments must take responsibility to maximise the opportunities to vaccinate. Such interventions do not address the (distinct) phenomenon of ‘vaccine hesitancy’ as we propose it should be defined.

The term ‘vaccine hesitancy’ should instead only be applied to those parents whose deliberations demonstrate something akin to *indecision*. However, the hesitancy concept will still not capture all who do not accept vaccines, since some parents may be decisive outright ‘rejectors’ of vaccines. Additionally, not all parents who have concerns refuse vaccines; in fact the vast majority of parents accept all vaccines on schedule despite some degree of concern [15]. Hence we concur with the WHO working group figure, which sees hesitancy occurring within a spectrum, from full and partial to no vaccination [16].

Since vaccine uptake is affected by both acceptance *and* the logistical or opportunity-related factors we described earlier, coverage figures cannot be a good indicator of vaccine ‘hesitancy’. Coverage (or lack thereof) gives no indication of any hesitancy on the pathway to full immunisation. Rather, purpose-built instruments are the only way to measure vaccine hesitancy [17–19]. Surveys developed (or under development) have focused on attitudes, safety, efficacy and behavioural constructs, such as trust, rather than access issues, which is entirely appropriate. Ongoing development and validation of these instruments across different settings will be important. Our engagement with attitudinal factors affecting uptake may also be enhanced by the use of existing terms that have been psychometrically validated, such as “decisional conflict,” which refers to a state of uncertainty about a course of action. Decisional conflict is an internationally accepted construct with a validated scale where certain scores correlate with action. Importantly, the measure has been shown as sensitive to change in a trial of a vaccination-related intervention [20].

There are other ways to identify the determinants of vaccination when working towards interventions to increase uptake. After reviewing studies, Thomson et al. [21] identified five fundamental causes of under vaccination: challenges to Access, Affordability, Awareness, Acceptance and Activation, a taxonomy referred to as the “5As”. These domains capture most determinants of vaccine uptake. Future research could validate their comprehensiveness, assess their relative contributions to under vaccination and evaluate their utility in informing the development of evidence based solutions to low coverage.

There is a need to develop and evaluate solutions tailored to the very real challenges of vaccine hesitancy (related to acceptance); these solutions are distinct from those needed for logistical problems (related to the other As). Finding and agreeing upon terms to clearly distinguish between vaccine hesitancy and the other determinants of uptake is an important start. We would suggest under-vaccinated as the over-arching term capturing those who are unvaccinated or partially vaccinated for any reason. Reasons for under-vaccination could then be further expanded into a set of constructs with good content and construct validity. Each needs development of different and tailored interventions to improve uptake. Only an accurate terminology can give us a clear idea of where the problem lies, allow us to assess its scale, and then focus our efforts accordingly. This way, our interventions have the very best chance of success in making vaccines available to those who want them, and to helping those who are uncertain about their vaccination decision.

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