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Evidence-based cervical screening: experts' normative views of evidence and the role of the 'evidence-based brand'

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Abstract

Organised cervical screening programmes are a combination of arrangements designed to maximise benefit and minimise harm associated with cervical cancer at the population level. Many organised programmes are described as 'evidence-based', reflecting an expectation that healthcare should be based on the tenets of Evidence-Based Medicine (EBM). EBM is both normalised and contested. As part of a larger study of how cervical screening came to be the way it is, we conducted a grounded theory study of cervical screening experts' perspectives on evidence and its use in guideline development processes. We sampled from several countries and across a range of professional backgrounds. Analysis was developed through transcript coding and memo writing, using constant comparison to develop insight and connections between concepts. We found that the 'evidence-based' descriptor was used rhetorically to indicate scientific trustworthiness; in short 'evidence-based' indicated 'good'. Experts held ideal conceptions of evidence and its use as objective and value-free, yet reported experiences that suggested those ideals were unattainable in practice. The 'evidence-based' ideal included restricting what counts as evidence to matters of science and epidemiology. This produced pronounced attention to matters of efficacy and effectiveness of cervical screening tests, and neglected decisions relating to the other arrangements that combine to produce an organised screening programme. Rhetorical use of the 'evidence-based brand' appeals to a particular kind of authority: one which is difficult to achieve in practice, and belies the variety of information that is required and the socially negotiated nature of policy and programme decisions.

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Evidence-based cervical screening: experts' normative views of evidence and the role of the 'evidence-based brand'

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Organised cervical screening programmes are a combination of arrangements designed to maximise benefit and minimise harm associated with cervical cancer at the population level. Many organised programmes are described as 'evidence-based', reflecting an expectation that healthcare should be based on the tenets of Evidence-Based Medicine (EBM). EBM is both normalised and contested. As part of a larger study of how cervical screening came to be the way it is, we conducted a grounded theory study of cervical screening experts' perspectives on evidence and its use in guideline development processes. We sampled from several countries and across a range of professional backgrounds. Analysis was developed through transcript coding and memo writing, using constant comparison to develop insight and connections between concepts. We found that the 'evidence-based' descriptor was used rhetorically to indicate scientific trustworthiness; in short 'evidence-based' indicated 'good'. Experts held ideal conceptions of evidence and its use as objective and value-free, yet reported experiences that suggested those ideals were unattainable in practice. The 'evidence-based' ideal included restricting what counts as evidence to matters of science and epidemiology. This produced pronounced attention to matters of efficacy and effectiveness of cervical screening tests, and neglected decisions relating to the other arrangements that combine to produce an organised screening programme. Rhetorical use of the 'evidence-based brand' appeals to a particular kind of authority: one which is difficult to achieve in practice, and belies the variety of information that is required and the socially negotiated nature of policy and programme decisions.

key words

evidence-based public health • cervical screening • qualitative research • population screening

key messages

- There is an expectation that cervical screening guidelines should be based on evidence.
- 'Evidence-based' is used rhetorically to indicate trustworthiness.
- Experts identified differences between EBM ideals and practice in developing screening policy.
- Many facets of organised screening programs do not have evidence to support them.

Introduction

It is well-established that cervical screening decreases mortality from cervical cancer at the population level (IARC, 2005). Yet it is less clear how cervical screening optimally works (Madlensky et al, 2003). Organised cervical screening programmes are a combination of arrangements made to maximise benefits and minimise harms of screening at the population level. Population screening involves making myriad decisions about many aspects of a test and its implementation. These decisions include such things as, for example, who to include in the target population, how often to screen, what test to use, who should carry out screening, how or whether to invite women to participate, and what, if any, data should be gathered.

In many parts of the world organised cervical screening programmes are described as evidence-based, yet despite the evidence base being global, these programmes look quite different to one another in practice, with significant variations in target populations, testing arrangements, tests used, and accessibility (Williams et al, 2014). There are increasing numbers of trials of new testing technology, such that some screening tests are now supported by a strong evidence base. How a test is implemented, however, is less well studied and more likely to depend on existing health system norms.

The expectation that cervical screening should be informed by evidence has strengthened with the rise of the Evidence-Based Medicine (EBM) movement. The principles and practices of EBM have a long history, but that particular phrase was coined and became influential in the 1990s (Claridge and Fabian, 2005; Evidence-Based Medicine Working Group, 1992), and evidence-based public health and evidence-based health policy followed soon after (Brownson et al, 2009; Niessen et al, 2000). EBM and its offshoots refer to hierarchies that rank types of information as evidence according to the likelihood of bias (defined epidemiologically), and consequently produce recommendations based on the type and strength of that evidence (GRADE Working Group, 2004; Petticrew et al, 2004; Rychetnik et al, 2002).¹

The ideal of evidence-based healthcare has been enthusiastically embraced, such that the use of evidence hierarchies in assessing clinical and population-level interventions is an expectation or requirement of many national bodies (NICE, 2014; NHMRC 1999; 2014; USPSTF, 2014). Indeed, the normative rhetorical power of evidence is such that to not be evidence-based is tantamount to negligence (Goldman and Shih, 2011). The successes (Godlee, 2014; Strauss, 2004) and shortcomings (Greenhalgh et al, 2014; Ioannidis, 2016; Kerridge, 2010; Little, 2003; Upshur, 2001) of EBM are the subject of a large body of literature. To use Sackett's often quoted definition, at its best EBM (and by extension, evidence-based healthcare more generally) is 'the conscientious, explicit, and judicious use of current best evidence in making decisions...' (Sackett et al, 1996). Recent literature has argued that EBM is being skewed by corporate and financial interests, resulting in 'salami-sliced, data-dredged' (Ioannidis, 2016) work and a 'misappropriation of the quality mark' (Greenhalgh et al, 2014). Another argument made by detractors is that EBM privileges and perpetuates narrow 'modernist and positivist' understandings of evidence and medicine (Kerridge, 2010; Upshur, 2001). We do not intend to reiterate these discussions here, other than to highlight that at the heart of debates about EBM are arguments about what evidence is considered useful to healthcare decision making, an issue of central importance in this paper.

Like other countries, Australia has a strong and explicit commitment to evidence-based policy (Head, 2008) and researchers working in medicine and public health are encouraged to focus on the translation of their findings into policy and practice. However, the uptake of evidence into health policy remains slow. The policy literature offers a number of explanations for why this may occur, such as misaligned research interests and a disconnect between the backgrounds of researchers and policymakers (Woolf et al, 2015). Other explanations focus on insufficient attention to socio-political factors and the policy context in favour of an overvaluing of (usually scientific) evidence. Head, for example, argues that three evidence bases are necessary for policy development: scientific, practical, and political (Head, 2008). Others explicitly devalue the role of evidence in policymaking, suggesting that its use may sometimes be more symbolic than substantive as a way of lending perceived credibility (Smith, 2013; Stewart and Smith, 2015). Importantly for this paper, Derkatch notes the importance of context on the interpretation of evidence; the same piece of evidence is differently persuasive depending on who is considering it for what ends (Derkatch, 2008). Much of this literature takes a policy perspective, but the setting for this paper is the development of clinical

and public health programme guidelines, which has traditionally been the domain of content experts. It is their perspectives on the use of evidence in guideline development, primarily in Australia, that we describe here.

While many of the evidence hierarchies developed to assist with policymaking are nuanced and recommend the use of different kinds of information in answering different questions, the idea of evidence is widely predicated on scientific objectivity; and the work that objectivity can do in constructing information as factual (Harrison and Checkland, 2009; Shulock, 1999; Young et al, 2002). Yet while objectivity is highly valued, it can be a contested concept (Goldenberg, 2006; Reiss and Sprenger, 2014). Objectivity is also often defined in terms of what it is not: that is, contrasted with subjectivity, individual opinion, uncertainty, or deciding based on values, ideologies and/or political interference (Montuschi, 2009).

In this paper we use the concept of the 'evidence-based brand', a phrase coined by Greenhalgh and colleagues (Greenhalgh et al, 2014) in the context of clinical medicine that we adopt and refine for our analysis of qualitative data from interviews with experts on the use of evidence in the development of cervical screening guidelines. Greenhalgh et al use the phrase 'evidence-based brand' to indicate a quality mark. We adopt their phrase and particularly focus on the 'evidence-based brand' as a label that has both normative and rhetorical power. This paper explores cervical cancer screening experts' normative constructions of evidence and its use in the development of cervical screening guidelines. We address the following research questions: (1) How do experts talk about evidence and its use in the guideline development process? (2) What does it mean when organised programmes are described as evidence-based? In our discussion we consider the ways the evidence-based brand interacts with implicit conceptualisations of evidence, what the brand does for the interventions it is attached to, and discuss the implications for organised cervical screening programmes.

Methods

The study was carried out using grounded theory methodology (Charmaz, 2006) and is based on semi-structured interviews with cervical cancer screening experts who were involved in developing guidelines for organised screening programmes.

Grounded theory starts with an open question, usually focused on a social process, and aims to generate an explanatory theory. This paper comes from a broader study funded by the Australian National Health and Medical Research Council that asked 'how did Australia's cervical screening programme come to be the way it is?'. In order to answer this question we began by sampling purposively and recruited Australian experts from the many professional backgrounds that are brought together under the cervical screening umbrella: pathology; gynaecology; general practice; epidemiology; public health; and public policy. We contacted those experts who were publicly identifiable as a result of their work in Australia. The participants in this study were selected for their work in cervical screening organisation, and not research methodology expertise. Consistent with grounded theory methods our working theory was developed as data analysis progressed. As we developed concepts based on initial Australian interviews with 14 participants we sought to test them against further interviews with cervical screening experts working in other countries. We were seeing recurring patterns in the data and wanted to see if those same patterns were present in data about different organised screening programmes. Testing emerging concepts with a group of participants that differs in some way from the purposive sample is a key tenet of grounded theory, and is known as theoretical sampling. We theoretically sampled five experts in New Zealand. We chose that country because its organised programme was developed just prior to Australia's and the

countries have fairly similar healthcare systems, though they differ with respect to some screening arrangements. New Zealand data were similar to those generated by Australian interviews so, in a third round of interviews, we sampled a further four 'international' experts. This third group of participants comprised those experts who are publicly identifiable as a result of their expert status internationally, that is, they have worked on a number of different programmes and on international expert guideline-setting committees. In grounded theory, data collection stops when the researchers consider they have reached saturation, meaning that they are confident that they have adequately interrogated all of the core concepts in the resulting theory. Twenty-three experts in total participated. The number of experts working in cervical screening organisation with a public profile in Australia and New Zealand is comparatively small and many of the experts invited had been active in guideline setting in the 1980s and 1990s, and this is reflected in the number of participants in our study. Internationally the pool is larger but recruitment was less successful.² Nonetheless, there was a great deal of similarity to previous data collection in this third round of sampling and we considered we had reached saturation. A majority of participants had experience working in cervical screening programmes in more than one country and we were able to sample experts who had been involved in organising screening from 1980s to 2014. Ethics approval was obtained by the Cancer Institute New South Wales Human Research Ethics Committee and the University of Sydney Ethics Committee.

JW conducted 22 interviews in person and by telephone. One expert declined to be interviewed but provided comments by email and consented to the use of that information for inclusion in this study. Telephone interviews have been shown empirically to provide data of comparable quantity and quality to that from face-to-face interviews (Sturges and Hanrahan, 2004). Interviews lasted between 35 and 91 minutes, with a median of 53 minutes. Interviews were recorded (except for one where the interviewee requested that the interview not be recorded but gave permission for written notes to be made during the interview), de-identified and transcribed verbatim. The question route changed as the study progressed, to reflect the developing analysis and to ensure each interview was responsive to the experience of the particular participant. Memos were written after each interview and again after each transcript was coded, allowing for the systematic constant comparison that forms the basis of grounded theory data analysis (Sbaraini et al, 2011). Rolling memos were written for each important concept, in which the lead analyst (JW) developed and compared the meaning of that concept in participants' talk. Due to the relatively small pool of cervical screening experts in some countries we do not include potentially identifying demographic information alongside the quotes in this paper.

Findings

In interviews experts talked extensively about 1) evidence and 2) the role of evidence in decision making. They talked in general terms about evidence and evidence use and also talked about specific evidence and instances of its use in committee-based guideline-setting processes they had been involved in. When experts talked about evidence in general terms they invoked a commonly-held normative conception of evidence: evidence was objective, scientific, and trustworthy. Because evidence was discussed this way, it enabled ideals around its use to be similarly framed. That meant that when they talked about how evidence was ideally used, they considered that it was able to override values and opinion to provide a 'correct' solution to questions of policy and practice because it was seen as factual. As a result of its perceived objectivity, use of evidence was assumed to provide a solution that would be acceptable to a variety of stakeholders.

During the same interviews, however, many of the experts also voiced disillusionment or frustration with evidence and how it was used in some of their experiences of decision making for policy and

practice. They remained supportive of the ideal role of evidence use in guideline setting but were critical of specific instances where they felt evidence or its application was inappropriate or inconsistent. When experts disputed evidence they focused on the perceived lack of rigour in its generation or the qualifications of its authors. Criticisms of how evidence was used focused largely on the reported conflicting professional values and interests of the people involved in the decision-making process. This dissonance between the ideal and descriptive conceptions of evidence was not, for the most part, acknowledged by participants; it was only by analysing across and between interviews that we were able to observe these contrasting perspectives in the context of the history and practice of organised cervical screening. All the experts we interviewed expressed the same ideal conception of evidence and its use when they talked about it in the abstract. Many, but not all, also described some experiences of evidence and its use that contrasted strongly with that ideal. Experts who contrasted the ideal with what they had experienced in practice did not appear to differ by country of origin or experience. There were, however, different views expressed according to stage of career and extent of involvement in guideline setting. Those who had experienced more than one guideline-setting committee process, along with those who had retired, were more likely to express disillusionment about the realities of evidence generation and use. Experts who were involved in guideline setting exercises at the time of interview were more inclined to describe observed practice that was aligned with the ideal, and more likely to use the term evidence-based as a descriptor. This may reflect shifts over time towards more rigorous application of standardised evidence-based processes in health policymaking. Alternatively it could highlight a greater willingness by more senior and retired experts with less at stake professionally to discuss the realities of compromise in decision-making processes, and the ways that other factors such as values and relationships make idealised practice difficult (Dobrow et al, 2004). Another possible explanation is that experts who have seen a number of 'evidence-based' policies developed may be more realistic about the compromises and political positioning involved in policymaking while still holding idealised views about evidence itself.

We present a summary of the findings in the figures below. Figure 1 shows the patterned differences in the way ideal and experienced evidence and its use were perceived and described by participants. Here we also hypothesise interactions between experts' expressions of evidence and the notion of the 'evidence-based brand' from the literature. The disappointment and frustration with what was considered inappropriate evidence or its use contrasted with ideals but appeared also to further bolster them. Ideas about what constituted ideal evidence fed into ideals about its use, even though what had been experienced tended not to reflect those ideals. Continuing to hold ideals meant that experiences of non-ideal evidence use were spoken about as if they were outliers, while in fact they were reported as very common.

Figure 2, below, postulates that the evidence-based brand helps drive ideal conceptions of evidence. Rhetorical use of the ‘evidence-based’ descriptor can have implications for what is prioritised when programmes are implemented, as shown using the example of the recent changes to Australia’s National Cervical Screening programme. Considerable time and resources were expended in evaluating the evidence around test characteristics and epidemiological outcomes when reconstructing this cervical screening programme. Very few resources were expended evaluating the considerable evidence base around programme implementation and women’s experience of screening. This suggests a skewed allocation of resources which supports an underlying bias in the kinds of evidence that are valued by programme designers.

We describe the relationships between evidence and the evidence based brand in further detail in the text that follows.

1 The normative functions of evidence and the ‘evidence-based’ brand and rhetoric

Ideal constructions of evidence and its use contributed to the sometimes rhetorical approach experts took to the ‘evidence-based’ descriptor. Befitting its role as a brand, and shorthand for quality, the term ‘evidence-based’ was widely applied to describe people, processes, programmes, and tests. Often the descriptor carried with it a sense of moral authority. An individual was described as “an evidence-based person” (E5) by an expert wanting to highlight the important scientific contribution of another. A programme was derided - “it’s not even evidence-based” – by an expert (E15) who intended it as a criticism of another country’s programme. ‘Evidence-based’ was thus a product of widely shared normative conceptions of evidence and how it was expected ideally to be used. As a descriptor it implied that this was a proven, science driven, and correct way of doing things. Interestingly, not evidence-based was used to mean different things: that either there was little or insufficient use of evidence; that the evidence was poorly interpreted and applied; or that the evidence used differed from the evidence valued by the participant.

2 Evidence was constructed as objective science

Evidence was presented as objectively factual information: experts tended to restrict talk about evidence to that which is quantifiable, and particularly to science, epidemiology or other

quantitative-data-driven information. 'Good' evidence was also implied by talk of what it was not: it was not subjectively influenced or derived from imperfect methods.

The ideal concept of evidence

When experts talked about evidence in general terms the words 'evidence' and 'science' were used interchangeably, for example: "I support HPV testing because I think that's where the science is" (E19). With only one exception, participants talked about the evidence base of cervical screening programmes explicitly and solely in terms of science or epidemiology that provided evidence about, for example, the best test to use, the severity of abnormality to follow up, or the interval between tests. Limiting talk about evidence in these ways framed it as quantifiable. Objectivity itself was implied rather than stated; experts' characterisation of evidence emphasised that it was not subjectively influenced, rather it was: "very sort of data driven, clinically data driven" (E5). The implication of the objectivity of evidence was further reinforced when experts talked about how it was ideally used, below.

Experience of evidence that contrasted with (and paradoxically reinforced) the ideal

Experts critiqued evidence they disagreed with by contrasting it with the ideal described above. They did this by emphasising the subjectivities involved in particular instances of evidence generation, and by undermining the qualifications or rigour of the people who had generated the evidence or the methods they had used. Examples of this talk include: "I couldn't for the life of me see how they could get this number in any sensible way" (E4) and "their numbers were wrong, everything was wrong, their assessments were wrong; it was all based on old stuff from years ago; pathetic" (E13). Describing their experience in this way reinforced the ideal by referring to their concerns about bias (personal, methodological, epistemological) in the generation of 'bad' evidence. The implication was that if this bias were removed (that is, if the science were done 'properly') then 'good' evidence would result and the ideal would hold.

3 The use of evidence was also constructed as value-free

Experts' talk about ideal evidence use was also predicated on the potential ideal (discussed above). Because experts assumed the evidence to be used should be objective, factual, and scientific, and because this objectivity was valued, scientific evidence had epistemic authority over other types of information (such as opinion or experience, for example). The assumption of objectivity meant that evidence was, in theory, able to be applied in a way that was acceptable to a wide range of stakeholders and could mediate in cases of difference of opinion: the objectivity of evidence was assumed to confer authority when it was used. Experts reiterated an ideal role for the use of evidence in part by contrasting it with their experiences, where that ideal use had been confounded or skewed.

Ideal evidence use

The purported objectivity of evidence meant that its ideal use was considered not to represent any particular interests and thus to be acceptable to all stakeholders. Some experts ascribed evidence with an important mediating role in potential cases of dissent. This was talked about particularly in relation to anticipated disputes between clinicians and epidemiologists, with such conflict having characterised decision making in cervical screening in the past. One expert, describing a situation where a committee might come into conflict over a particular point, said "if a committee is colliding with a wall, it doesn't collide with a wall of evidence. Evidence helps make a decision" (E11). Another said "I really, strongly support the evidence-based approach. I think it's exactly the right thing to be

doing. And, ultimately, um, you know, ultimately, it's the way to get the consensus in the end, and do it – do it properly and do it carefully" (E9). Ideal, therefore, was a situation where committee members would be presented with evidence that was perceived to be 'true' as a result of its objectivity, and that evidence would be sufficient to steer decision making.

Experience of evidence use that contrasted with the ideal

In contrast to the idea that evidence can mediate disputes, another expert describing her experience of a committee process said the evidence presented to that committee had triggered "basically a year, or six or seven months of, you know, hysterical epidemiological wrangle" (E13). Other experts, describing situations they had experienced, spoke of bitter conflict over whether or not particular types of evidence were appropriate to guide decision making in particular situations. An example of this was disagreement over whether the management of clinical problems that presented in cervical screening should be guided by population level evidence. In practice, experts from clinical and population health backgrounds often anchored their positions to different kinds of evidence: "the evidence didn't support the view of some of the people, I think the specialists... it became very bitter" (E8). Disillusionment over evidence use was seen as a disappointing inevitability. Experts who had worked in a number of programmes consistently described the same conflicts between clinical and epidemiological approaches to cervical screening decision making. Yet at the same time, they continued to hold to the ideal of evidence having the potential to broker decisions.

4 Evidence-based cervical screening tests

Importantly, when experts talked about evidence and its use, both in the abstract and in the context of their experience, they referred only to evidence about cervical screening tests. Experts did not refer to evidence when talking about how a programme should be run, which includes those many aspects that are recommended by IARC to be carried out according to local conditions (IARC, 2005). Such aspects of screening include, for example, how to inform and engage women in the programme, or how to manage quality assurance and pathways from the initial screening encounter to investigation and treatment. Many of these decisions that determine the effectiveness of an organised screening programme are currently not supported by the type of information that the experts would refer to as evidence or consider to meet the ideals of the evidence-based brand. Importantly then, when experts referred to 'evidence-based screening programmes' they were in fact talking about evidence-based cervical screening tests. We take up this point in the discussion about the implications of the rhetorical power of evidence-based brand for programme implementation.

Discussion

We have described a gap between experts' ideal conceptions and their reported experiences of evidence generation and its use. The existence of this gap is not unexpected. There is wide acknowledgement in the literature of the difference between ideal and actual evidence use in policymaking (Campbell et al, 2009; Elliott and Popay, 2000). What is notable is the frustration many experts expressed with 'non-ideal' forms of evidence and its use. It implies a strong attachment to the ideal and tacit rejection of the realities of how negotiated policy decisions are made – despite our participants' extensive experiences of committee-based decision making. We also found that 'evidence-based' was used as a normative descriptor (Finding 1), and that conceptualising evidence as an idealised form of science restricted what aspects of screening the experts discussed (Finding 4). We elaborate on the latter two points below.

Evidence use is important and we do not question its proper foundational place in decision making about the design and implementation of public health programmes such as organised screening. While acknowledging the ongoing challenges (Greenhalgh et al, 2014; Ioannidis, 2016), when intervening in populations, it seems prudent to seek as much scientific and epidemiological information as possible about the benefits and harms of particular screening tests, so as to maximise those benefits and minimise harms. That evidence and its judicious application are highly valued indicates a broad support for departure from the decision making based on arbitrary judgement or absence of evidence that characterised some policymaking in the past (Greenhalgh, 2014). While there are clearly benefits to systematic approaches to evidence assessment and use, we wish to call attention to the work that normative conceptions of evidence do in the negotiated processes of guideline development for organised cervical screening. There is considerable attention in the literature to how evidence use in decision making can be nuanced and adjusted to embrace a variety of forms of evidence, for example (Brownson, 2009; Dobrow et al, 2004; Rogers, 2004). There is also acknowledgment of what has been described as a confrontation over different rationalities (Boumans, 2008), where experts from different epistemic backgrounds prioritise different kinds of knowledge (Fernler, 2015; Williams et al, 2016). Despite this, and despite experts' personal experience of the intertwining of evidence and values, the ideal of objective, truthful, and value-free evidence use appears to remain commonly held. In this discussion we explore: 1) how the common reference to the evidence-based brand shapes what counts as evidence; and 2) how use of the evidence-based brand affects the implementation of organised cervical screening programmes.

The evidence-based brand indicates what evidence counts and what interventions count

The original coinage of the evidence-based brand indicated its role as a quality mark (Greenhalgh et al, 2014). Here we wish to extend Greenhalgh et al's phrase to focus on what the rhetorical use of 'evidence-based' can do. We suggest that the evidence-based brand contributes to shaping what evidence is considered, and how that evidence is considered. Evidence hierarchies are explicit about the importance of avoiding bias; the claim made is that the greater the capacity of the study design to eliminate bias, the higher its quality and applicability (NHMRC, 1999; OCEBM Levels of Evidence Working Group, 2011). Hierarchies therefore guide the type of evidence that counts: 'evidence-based' means the systematic and comprehensive use of evidence that avoids bias (Kerridge, 2010). It is a short leap from the avoidance of bias to a particular ideal of objectivity. That cervical screening experts adopt evidence hierarchies, particularly in a climate of strong expectation of evidence-based practice, is thus unsurprising and justifiable. With that said, evidence informs at best only a part of how decisions are made for public health programmes such as cervical screening. Attaching the label of 'evidence-based' to an intervention infuses it with the same normative power we identified in our analysis of experts' talk about evidence; applying the 'evidence-based brand' to a programme is a way of harnessing it rhetorically to the authority and trustworthiness of science. In a nutshell, 'evidence-based' indicates 'good'. So arguably, when entire programmes are described as 'evidence-based', but only a minority of decisions made in that programme were explicitly based on evidence, the 'evidence-based' label may be problematic.

We know from our interviews with experts that the realities of negotiating cervical screening policy are often difficult and characterised by conflict and compromise. The subjective messiness of evidence generation and application, and policymaking more broadly, tends to be hidden behind the evidence-based brand (Dobrow et al, 2004; Klein, 2000; Weed, 1997), creating for those not involved in the policy development process an 'evidence façade' (Bambra, 2013). The implication that decisions are made solely on the basis of evidence is a misrepresentation. In the case of a programme that involves many decisions about many aspects of practice, using the label

‘evidencebased’ implies use of evidence across the board. This is very unlikely to be an accurate portrayal and we take up this issue when we discuss the implications of the brand for programming. Honesty in communication, including public communication, is something that would be reasonable to endorse in principle in most cases. Where there is pressure to be ‘evidence-based’, the label may increasingly be used rhetorically to suggest global quality rather than the precise and technical process that it was intended to portray.

Implications for policy development and programme implementation

A reductive, scientific conception of evidence is only equipped to handle certain research questions, yet our findings demonstrate that it remains at the heart of many experts’ conceptions of evidence-based practice. In the context of cervical screening, the questions most likely to comply with this conception are those about the efficacy and effectiveness of particular tests. Being able to apply the evidence-based brand to an intervention is a desirable outcome of policymaking, and it remains likely that priority will be given to areas that can be studied scientifically and epidemiologically. Practically, for cervical screening, this means a focus on the efficacy and effectiveness of screening tests. Conversely, it means that areas of the programme that are likely to need other investigation methods, or that use evidence that is lower on established hierarchies, are unlikely to receive the same rigorous attention in decision making. These areas include those many aspects of implementation that are best considered using evidence derived from qualitative, observational, or mixed methods studies which continues to be less highly valued than evidence generated through quantitative methods (Greenhalgh et al, 2016). Examples of evidence that could inform implementation of cervical screening programmes include studies of public acceptability of proposed or actual organisational changes (of which there are currently many), or what makes some women more likely than others to follow up on abnormal screening results. This kind of information has the potential to improve women’s experiences and programme outcomes, but is likely to be overlooked due to perceived rigour when assessed on the EBM hierarchy.

When normative conceptions of evidence combine with rhetorical uses of evidence-based descriptors, rigorous appraisals of screening implementation are de-prioritised by those involved in policy decision making. Programming must encompass the specificities of particular healthcare systems, such as the culture attached to privacy or preventive healthcare, tensions over use of scarce resources and so on. There is significant variation in how screening programmes are run, both across and within countries (Williams et al, 2014). Modifications such as targeted screening information, special access arrangements for specific populations, and different funding arrangements for different groups are in place in a number of countries including Australia and New Zealand. Appropriately, studies addressing local issues tend to be focused on a particular population: what information does this group need? How can the programme be made more relevant for a particular sub-population? Are we able to introduce nurse-led screening in a system where GPs are compensated in a fee for service model? The types of information that inform optimal programming are less visible, less generalisable, and much less valued than large-scale international studies of test efficacy. As a result, processes surrounding all of the local decisions that are made on how to run a programme tend to be obscured because they do not have the rhetorical status of being ‘evidence-based’. However these decisions determine access and acceptability and are thus likely to have significant downstream effects on women’s experience of the programme.

Conclusion

Debates about EBM and what it is to be evidence-based have been ongoing since the convention was conceived and popularised. As mentioned, more recent debates have tended to focus on what

can be hidden under the auspices of EBM: the interests of industry, ghost-written papers and redefinitions of disease, to list just a few (Greenhalgh et al, 2014; Ioannidis, 2016). These frustrations are based on the premise that EBM is a worthy enterprise and that it should and can be reclaimed to achieve what it was intended to do. Our findings portrayed a similar frustration among cancer screening experts who reported their experiences of guideline development as straying from the evidence-based ideal. We have also noted how the rhetorical use of the evidence-based brand for cervical cancer screening programmes appeals to particular kind of authority, one which belies the variety of information that is required and the socially negotiated nature of policy and programme decisions. There have been suggestions for ways that evidence should be used to best support screening programmes. Epidemiological evidence is an important source of information for screening. However, other kinds of evidence are also important, such as evidence about screening as a social issue, and evidence derived from empirical ethics studies (Rychetnik et al, 2013). These three evidence types can be incorporated into USPSTF-style reports of screening that attach individual grades of recommendation to different aspects of an intervention or programme. Such an approach would appease the need for thorough assessment of test efficacy and effectiveness, but also attend to those vital social decisions that are currently obscured by the 'evidence-based' label.

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Notes

¹ Evidence for the effectiveness of cervical screening and the organisation of cervical screening is based on study types (usually cohort and case-control) that are low on the evidence hierarchy. This is because by the time Randomised Controlled Trials (RCTs) were considered best evidence, Pap testing was considered effective and was widely implemented. This meant it was not ethical to randomise women to no screening in countries where screening was already in wide use and equipoise was not considered to exist. New tests for cervical cancer prevention, particularly HPV DNA testing, have led to an explosion of new studies in cervical screening. These include large-scale RCTs and systematic analyses that compare various modes of screening, providing higher-level evidence than has been available in the past.

² In Australia, 20 experts were contacted. 14 agreed to participate, one declined, and five did not respond to email or letter (it is not clear whether or not contact details were current). In New Zealand, we invited six experts to participate. Five consented and one declined. We contacted ten international experts. Four agreed to participate and six did not respond to emails (to addresses we consider were likely current).

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