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More than just a chat – the experience of bringing service user involvement to an online community of practice

Abstract
The Department of Health (DH) advocate Communities of Practice (CoPs) are a key vehicle for delivering service transformation (DH 2011). In 2012 a health visitors' online community of practice (Ikioda and Kendall 2014) extended the concept through a web supported platform. A recent development involved a closed Facebook Group to bring a group of health visitors and service users together through a series of online "chats" aimed at learning more about the service user perspective of receiving an evidence based service. In this paper the authors explore the experience of service user involvement in the interpretation of research based practice drawing on the narratives of both groups and consider the impact this could have on service delivery.
Key words; public health nursing> evidence based practice> parents> consumer involvement >social media

Introduction and policy context
CoPs are described as a mechanism that helps to bring codified knowledge from research based policies and guidelines into practice (Lave and Wenger 1991, Wenger 1998). Central to the *HV Implementation Plan* (DH 2011) CoPs have been recognised as vehicles to deliver individual professional development and improved service delivery because they support much better engagement with other practitioners and more opportunities to participate in health visitor innovation (Kislov, Walshe and Harvey 2012). The DH advocated that CoPs supported by Early Implementation sites (EIS) were central to the transformation of the service through adoption of the *4-5-6 Model* (DH 2015) The model is intended to improve outcomes for children by targeting inequalities and enhancing engagement between parents and health visitors

The importance of online technologies to practice development
Online technologies have influenced the development of virtual CoPs to support geographically dispersed health care professionals who share a domain of interest and help them form wider networks than would otherwise be possible (Lathlean and Le May 2002). Social media platforms such as Facebook and Twitter have helped to facilitate this further (Barwick *et al* 2009)

In 2012 a health visitors' community of practice evidence hub (HVeCOP) was piloted in Tower Hamlets and Hertfordshire (https://cophv.evidence-hub.net) Developed in partnership between the Open University, the Institute of Health Visiting and the University of Hertfordshire it is open to any health visitor registered with the NMC. Currently the HVeCOP has 650 users who can contribute issues or questions from practice, share current practice that addresses those issues and post supporting and counter evidence that relates to practice. As the first platform of its kind exclusively for health visitors it enables discursive debate and has the potential to help practitioners take more control of the interpretation

and evaluation of the evidence they work with and achieve a greater degree of professional autonomy.

In 2015 the HVeCOP opened a Twitter account (@HVeCOP) to promote the platform and support adoption. This was part of a series of master-classes offered to health visitors by the Institute of Health Visiting "Making the Most of Health Visiting" campaign funded by the DH at the beginning of 2015. Through connections made on Twitter, HVeCOP has engaged with a wide network of child and maternal health care providers and users and supported health visitors to adopt the use of technological resources. Chin (2014) advocates the relevance of social media for every day practice because online conversations can help them enhance their role, listen to the views of their own profession and extend their interest to the views of service users, stakeholders and service providers.

The voice of service users
Calvert (2015) has written about the need for health visitors to recognise that parents are actively engaging in online technologies to build their own support networks and gain access to much greater sources of information. She argues this is challenging how health visitors engage with and use the evidence base they work with. These views are based on her experience of setting up and facilitating a private Facebook group for parents. It started in 2011 as a way to bring mothers together to discuss parenting issues and share advice. It quickly grew and now has over 2,000 members across the UK and internationally. An administration team of 10 people with a wide variety of professional expertise and parenting experiences promote and moderate evidence-based information as well as offer a point of contact for individual members. A website linked to the group displays the bank of evidence based information which the group has built up (https://themumvillage.wordpress.com) Many members report finding the group useful because it offers non-judgemental support 24 hours a day, that is friendly and tailored to the individual mother, and includes recent evidence. Women are encouraged to share good advice based on their own experiences as well as seeking information for themselves so the group is not only sought out when problems arise. However, Calvert also argues that based on their posts to the group it seems not all mothers are aware of the full role of health visitors and can have difficulties with their service but have no idea how to tackle this or request a more helpful service. These accounts and the development of a linked website suggests that important sources of information based on the experiences of the group and moderated by the administration team could contain an important dimension to the interpretation of the evidence base health visitors work with.

As part of the pilot for HVeCOP (2014) parents were involved in focus groups and contributed to the evaluation of the project (Kendall *et al* (2015) They reported receiving conflicting advice and lacking an understanding of the health visitor role so to some extent their narratives echo the experiences of the Facebook group. They felt the hub tool could be a way of amalgamating their real life stories as evidence which could be applied to other situations and improve understanding of the role. Kendall *et al* (2013) drew on these accounts and the contributions from health visitors to suggest that the platform had

identified gaps in evidence available for professional practice and argued that more work needed to be done to highlight what evidence health visitors required.

The concept of service user involvement has a strong mandate in policy. The Health and Social Care Act 2012 specifies the legal duty of service commissioners for NHS England (NHSE) to enable patients and carers to participate in planning and making decisions about their care and treatment. NHSE (2012) prioritised improved approaches to participation particularly for those experiencing health inequalities in their response to the Marmot Review (2010), which measured the difference in life expectancy between socio-economic groups. Marmot argued improved penetration of interventions intended to tackle inequalities have greater impact if there is effective participatory decision making between health care service providers and people who have difficulty accessing them. The *4-5-6 Model* (2015) draws on these research and policy recommendations to ensure equal access and early intervention as the basis for reducing inequalities. Potter *et al* (2015) concluded that service user involvement is perceived as a different way of learning by student health visitors because it provides the opportunity to participate in honest accounts of their experiences and confront professional attitudes that may limit access to services. Based on Calvert's account (2015) the evaluation of the pilot project (2014) and current policy members of HVeCOP and the parents group agreed to collaborate on exploring a way of bringing the propositional evidence from service users to the platform.

The development of a private Facebook Group between HVeCOP and a group of parents
A private Facebook group was set up to facilitate conversations or "chats" between the 2 groups. The first "chat" took place in November 2015 with an initial discussion between 6 members of HVeCOP and 7 parents. It explored the expectations of both groups and considered what opportunities there were to learn more about how evidence based practice is experienced and influences parents' decisions. Ground rules for the group were agreed beforehand and the page is only open when a "chat" is taking place. Most importantly it is not a forum for health visiting advice or a replacement for a service. Two further discussions have taken place since November which have focused on specific issues and have been chosen and facilitated equally by members from each group and continue to attract the same ratio of parents to health visitors. A paediatric dietitian was invited to join the 3rd discussion on weaning as a guest and there is also a policy of encouraging the initial group to invite new participants.

The first discussion concluded with agreement that a series of "chats" could help to find ways of improving communication and building trust as the basis for learning how to enable a more shared approach to the interpretation of the evidence base.

"Would like evidence presented to us to check ourselves….I think it's the way it's put across"
Parent 1 introductory chat

"We know that so much of what we say based on evidence isn't what (necessarily) happens"
Health visitor 1 introductory chat

Anxiety about giving honest feedback and lack of trust were seen by parents as the main barriers to achieving this based on their experience of not knowing how to tackle negative experiences about their service

"Problem is parents are worried HV will know it's them (giving feedback) and it'll be awkward in clinic" **Parent 2 introductory chat**

Both groups expressed a willingness to provide an insight into areas they felt could be improved and were open about not necessarily having the answers to each other's questions or how to remove the barriers preventing a more non-judgemental and accessible service. On this basis participants from both groups expressed an interest in having more online meetings.

"I haven't heard too much in my practice about what parents want but lots about what they don't want ……. I really want to know what parents need from us" **Health visitor 2 introductory chat**

"I didn't know what I wanted …. The last thing I wanted though was another person coming in to tell me what to do when I hadn't figured it out for myself yet" **Parent 3 introductory group**

"I think it is time so that parents understand HVs aren't there to interfere but support if needed….it all comes down to relationships. Why is that such a problem?" **Parent 4 introductory group**

Learning about improved communication
Parents have felt able to talk about their experiences of how information is given to them routinely and how this has influenced their confidence and trust in the service and their willingness to engage with it. In the second discussion about parents' bed sharing with their babies several participants said they had only been told not to bed share not how it could be done safely. They felt this ignored current evidence (NICE 2014) and the potential benefits to mother and baby such as successful breastfeeding and less sleep deprivation both of which were contributors to improved maternal mental health. These views were drawn from their own experiences as well as their understanding of the evidence related to reducing the risk of cot death posted on their website. One parent participant who is a peer breastfeeding supporter reported that some mothers she worked with lack confidence to talk openly to their health visitors because they are fearful of being judged

"Sadly…I find.. mothers' don't feel confident talking to their HVs as they are fearful of the "consequences" **Parent and peer supporter chat 2 on bed sharing**

"I was told it (bed sharing) wasn't safe ……having spoken to the other Mums (on their Facebook group) and read about bed sharing it made sense to me and not scary"

Parent 4 chat 2 on bed sharing

"I think so many parents accidentally fall asleep (sitting up) with a new born on their chest that it's a good idea to lower the risk (being told how to safely bed share) than just say "that's dangerous" which is what I was told with my oldest. This just led to more guilt and less sleep"

Parent 5 chat 2 on bed sharing

In response health visitors have felt able to explain how professional guidance and the context in which they practice can be experienced as a barrier between how they communicate evidence to parents as well as share feedback with each other about the evidence and how they understand their accountability as practitioners.

"We are very constrained by what we say sometimes. We have to follow Trust policy …… even if we believe that bed sharing can be very beneficial and are up to date (with evidence) ….we still have to follow Trust policy. ….I fully support mothers who tell me they are co-sleeping and welcome the opportunity to go through the safety aspects very thoroughly whilst being obliged to explain that is currently against Trust policy…"

Health visitor 3 chat 2 bed sharing

"Just to put this out there….we have a responsibility to our NMC code of practice and the clients…after that Trust policy is important. The day health visitors do not provide evidence based information to their clients because of Trust policy is a grave one"

Health visitor 5 chat 2 bed sharing

Potential to share decisions about how evidence is interpreted

The initial discussion suggested shared decisions about how evidence is interpreted was perhaps the most important aspect of parents' relationships with their health visitors because they felt it is the basis for building trust and having a more equal relationship. During the third "chat" about introducing solid food the evidence related to exclusive milk feeding demonstrated how complex interpretation of evidence can become if practitioners rely exclusively on practice guidelines as new evidence becomes available. Within this context parents can be a valuable support in negotiating a way through that complexity by sharing the understanding they have of the same evidence as well as promoting their parenting preferences.

"I have spent the last few weeks reading evidence and guidelines ….then I read the most recent research on (preventing the risk of) allergies. I haven't changed my mind about the guidelines for weaning at 6 months ….but would (now) happily support parents who believed their baby is ready to wean at 5 months and would share the current advice the same"

Health visitor 2 chat 2 weaning

"If I hadn't had the group I would have been at a loss when I wanted to find out as much as I could about leaving weaning until 6 months. I tried to talk to a HV (who said) ….wait until 6 months then they can have anything to eat……I didn't think that was true and thought it best to start gently and could have taken the "pretty much anything" literally

Parent 3 chat 2 weaning

Discussion

Seal (2008) argues it is important to know why professionals and organisations want to involve service users and what they want to achieve from it to avoid confusion and tokenism. HVeCOP expressed an interest in learning more about service user experience of accessing sources of research alongside receiving an evidence based service to help them explore current practice and develop their online CoP. Calvert (2015) felt the most significant aspect of receiving an evidence based service was for parents to be able to make their own decisions based on accurate information offered to them by health visitors. She questioned the power dynamic between health visitors and service users where the health visitor makes the decision to offer particular advice from a particular perspective without first also explaining counter evidence which may question that practice. Interestingly, this has been studied in previous research by authors such as Kendall (1991) where, based on conversation analysis of 62 HV-client interactions, health visitors were shown to often provide unsolicited advice as a strategy for managing the encounter and to discard parental expertise. This research, alongside that of others such as Sefi and Heritage (1992) has not been fully embraced by the profession. A more recent unpublished PhD (Mumby-Croft, 2014) has also shown that currently there is a tendency for HVs to adopt a more powerful position in the encounter with parents in the clinic situation. Seal (2006) defines the type of approach to service user involvement which challenges power dynamics as a critical perspective which goes beyond a consumerist and rights perspective towards a radical desire for change through questioning and breaking the power balance. Seal (2006) also describes a process called institutional distancing. This explains a form of resistance to services as a way in which users construct their identity. The experience of the Facebook group can be considered within this analysis because institutional distancing to aspects of the health visiting service has been an important part of their transition into parenting and their development as a group. However Calvert also makes a strong case for the health visiting service because parents recognise their practice is grounded in training, experience and evidence based knowledge. This reflects Cowley *et al* (2013) findings from their review of academic literature on service users' experiences of health visiting that parents want advice and support from a trained health visitor and say they feel tangible benefits as a result. So is it a particular type of service delivery this group of parents resist not the service in its entirety? If it is then perhaps the wider challenge for health visitors may be how to deliver a service model which values service user led development and a more equal relationship where ownership of the evidence base can be more balanced. In a later literature review of the public health benefits of a universal health visiting service Cowley *et al* (2014) again found confirmation of skills values and attributes which define health visitor practice but also recognised this wasn't always the service which was delivered and in particular highlighted deficits in communication skills such as advice giving before fully

exploring the client's perspective which acknowledges the experiences reported through the "chats"

Finlay (2000) argues establishing an expert knowledge base is important to professional groups because it defines their credentials as experts and because it can be investigated and validated. Tuckett et al (1985) present accounts of patient and GP encounters where professional expertise is seen to be privileged over client or patient expertise suggesting client interactions can be a contested process. For example scientific knowledge where some of the evidence for health visiting practice comes from has a greater validity than the vocational or prepositional knowledge of parents which is likely to be more grounded in experience drawing on their own reading and interrogation. Harding *et al* (2010) argue research suggests non-expert involvement in service development is not always accepted because of differences in knowledge, ideologies (Fudge 2008) and perceived status (Ion & Beer, 2003) The 2 studies by Cowley *et al* present findings from research which describe how this occurs in health visitor/client interactions and its relationship to poor uptake of services. It should also be considered how representative these particular narratives are compared to service users as a whole (Martin 2008; Hamilton 2009). However Robert *et al* (2003) argue users' views can be considered as a snapshot of the wider service user experience and representativeness should not be seen as an obstacle to their value. Further, based on the narratives of participants of this group of service users and health visitors there is agreement to collaborate on how evidence is interpreted and used which has been shared on HVeCOP (Newsletter July 2016) which could potentially start a process of change in how evidence based knowledge is given to parents.

Box 1 Participator perspectives on their experience

"The group's feedback has been an immensely valuable insight for my practice……I can still hear their words on my most routine activities"   **Health visitor participator 1**

"A very safe place in which I feel my opinions and ideas are heard and are a benefit (to participators in the chat)"   **Parent participator 5**

"I wasn't sure (about the chats) at first particularly communicating online which is very new for me – it's never easy to hear criticism of our role particularly when we may have some agreement with it but can't easily influence change – but I have found myself enjoying the experience particularly learning how to improve what we deliver even if we can't always change the service itself"
                    Health visitor participator 7

"I have enjoyed being part of the group so far……I like the open honest approach, and basing response on experience I think is important."   **Parent participator 5**

"……an added benefit is the HV service can be promoted as a service that is willing to listen and be responsive…….whilst also allowing open and honest discussions when challenges arise"
                    Health visitor participator 8

Cowley *et al* (2013) concluded that research into collaborative approaches to service user design delivery and evaluation is scarce. Bidmead (2015) reports on the published educational standards for health visitors published by the iHV (Bishop *et al* (2015) which acknowledges the need for health visitors to receive feedback from service users regarding the effectiveness of their interventions. Both Cowley *et al* (2013) and Bidmead's (2015) observations suggest that a greater degree of service user involvement which can be measured is desirable to both the evidence base and to relationship based practice. It can also be argued that this could begin to move the debate away from a consumerist model of service user involvement towards a more politicised model of empowered change for both health visitors and service users.

Conclusion

The experience of this series of online "chats" between parents and health visitors suggests that both groups want more than simple involvement of service users, which risks being tokenistic. It also suggests that their shared aims to learn from the service user experience has gone further than tokenism by demonstrating a willingness to be responsive. Whilst it may not be possible to claim that a completely shared approach has been adopted, the opportunity to communicate through online technologies and the agreements put in place from the first exploration of a rationale for having them suggests there is a mechanism in place with the potential to support work which could achieve it. McKeown *et al* (2014) argue that progressive change in service user involvement can happen when certain conditions such as these are created. Health visitors who are willing to collaborate with service users through an online community of practice have a real opportunity to engage with and support such praxis based on their interest in exploring radical change. Their experience also suggests it is possible to find a safe space where the interrogation of the evidence base through a process of discursive debate can be shared more equally with the possibility of identifying new approaches to evidence based practice and a greater level of engagement by service users, particularly as it is intended that the online "chats" will continue. Their content has been published on HVeCOP for the benefit of the wider profession and the opportunities it offers to the development of relationship based practice

Key Points

- Involving services users in the development of an online community of practice can provide an opportunity for dialogue where professional dominance is challenged
- Health visitors have been able to use participation in online "chats" with service users and colleagues to question their practice
- Online technologies provide an opportunity to explore a different approach to engaging with service users and the potential for radical change
- Service user led decisions about how evidence is shared with them is central to improving relationships with health visitors

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