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HEALTHWATCH INVESTIGATIONS

Developing good practice

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Background

Investigating issues and concerns raised by service users, carers, patients and the wider public and getting feedback, is core business for local Healthwatch. This is an extremely challenging role. Local Healthwatch are small organisations who are charged with influencing large organisations and local health systems.

In order to be successful local Healthwatch have to provide an analysis of the experiences of the public in a way that is credible and understandable to large organisations who will have much greater analytical and professional expertise and who may feel (rightly or wrongly) that they have a better grasp on what the challenges are and 'what needs to be done' than a local Healthwatch!

This report summarises some of the thinking and practice that has emerged from work that has been led by Health Together¹ and involved Healthwatch Leeds, Healthwatch Wakefield and other local Healthwatch in West Yorkshire - Bradford, Calderdale and Kirklees - as well as a briefing session facilitated by Involve Yorkshire and Humber which was attended by a further six Yorkshire and Humber Healthwatch.

Is an investigation research? What is good ethical practice?

We consider it is better to describe the process of investigation carried out by local Healthwatch as 'gathering intelligence' or 'conducting an investigation' rather than research because local Healthwatch are generally not involved in research as it is formally understood by academia or the NHS.

This approach means that local Healthwatch are not bound by the same criteria with regard to formal ethical approval. However it is still important that local Healthwatch work in a way that they consider to be ethical and which they can justify to any critics.

This should include a good practice ethical statement agreed by the local Healthwatch Board and available to members of the public and other stakeholders. It might be expected to include statements about how the following will be assured in any investigation:

- Confidentiality and anonymity (occasionally, some informants may need to be identified to make sense of their feedback – but only with their written permission).
- Data Protection – how will any data be kept secure? Who will have access to it?
- Code of conduct for staff/volunteers setting out how they should behave when investigating and when it is appropriate for volunteers to be involved and when not.
- Voluntary participation – everyone taking part knows what the investigation is about and what is expected of them and also how they can withdraw themselves or anything they have said. This needs to be written down in an information sheet which participants have access to.

¹ Health Together is part of the Institute of Health and Well Being at Leeds Beckett University part of its work includes delivering work for Healthwatch Leeds and Healthwatch Wakefield. Follow this link for details: <http://www.leedsbeckett.ac.uk/healthtogether/>

- Health and safety considerations – for example this might relate to where the investigation is conducted and to both those conducting the investigation and those participating.
- Support for participants who might feel anxious about giving feedback or find it raises issues for them (including emotional ones) or highlights things they would like further information on.

So, although not formal research, there is much that local Healthwatch can learn from research practice to make their intelligence gathering as ethically rigorous and credible as possible.

Credible Investigations

Participants in our workshops raised many challenges that local Healthwatch are facing in conducting rigorous and credible investigations:

- Data
 - o Recording information in a consistent way so as not to miss any intelligence coming in to the organisation
 - o Accessing relevant data kept by other organisations – developing trust and then protocols
- Key Relationships
 - o Reaching the people you want to get feedback from not just those who are easiest to contact
 - o Approaching people and motivating them to take part
 - o Avoiding ‘consultation overload’
- Prioritising
 - o Deciding which issues to investigate further and how to prioritise particularly where the priorities of users and the public might be different from commissioners or providers
 - o Managing expectations from stakeholders including members of public who have an issue they are passionate about and think should be prioritised
- Policy Expertise
 - o Having sufficient knowledge of the ever changing health/social care system
- Research Methods
 - o Getting a limited amount of information from lots of people versus more in depth from a few – how do you decide which is best?
 - o Deciding which methods to use and when and feeling confident to use them

- Knowing how to deal with responses from people who do not know who their service provider is and/or understand how the service operates
- o Making sense of loads of data – how to analyse/interpret
- o Presenting information – how to make it accessible to a range of audiences.

When to investigate?

With limited resources local Healthwatch need to give careful consideration to which issues to investigate further. Boards need to set priorities but also leave some flexibility for the unexpected. Issues which start to emerge and need to be weighed against these priorities.

It may be that an issue is serious enough to raise safe-guarding concerns which need to be taken straight to the relevant authorities. Or it may be that a one off visit, or feeding back comments direct to a service, may be sufficient and an investigation is not needed. If it looks as though an issue might warrant an investigation, then it is important to validate any concerns before proceeding.

- Is the issue being raised by different interest groups?
- Does it fit with existing intelligence/knowledge that is coming through the local health system?
- Has local Healthwatch the resources to follow through any investigation that is started?

Planning

Once the decision has been made to conduct an investigation then it is extremely important to gather some background information and make a clear plan before 'diving in'.

Establish support

We have found that if it is a new or complex issue then it can help for a local Healthwatch to involve a wider group of staff and volunteers to contribute to through group discussion at key points of the investigation. This group could help develop and/or sense-check the plan and provide a critical voice - for example when analysing the data. This helps bring some safe challenge before going public and also builds capability and knowledge within the organisation as a whole. It may only be two or three people but there should always be an 'investigation team' to decide on the approach and act as a sounding board, even where there is one person leading and doing most of the work.

Context - Policy and Practice

With any issue there will be a context. In particular it is important to have some understanding of the current policy position and to establish whether there is already a clear view of 'what good looks like' with regard to the issue you are about to investigate. For example:

- Does a leading specialist voluntary organisation, industry body or regulator have a clear view that can be used to benchmark any investigation?
- Are there practice standards that have been adopted locally? Having clarity on this will give you a measure against which to judge what you find when you start gathering intelligence.

- Has the issue or service been the focus of any other inspections recently – by the Care Quality Commission, LINKs, or internal to the organisation which the service is based in?
- Where does the service under investigation fit in the pathway of health care and support? For example experience at A&E is in part determined by ‘upstream’ issues such as access to General Practice and Walk In Centres. Similarly experience on a ward for older people might be determined in part by ‘downstream’ issues such as availability of adult social care support in the community.

Sound Bites and Spin

It is also important not to assume that the headline issues that are emphasised in Government policy and the media are the ones that actually reflect people’s concerns on the ground. For example:

- Is choice a key concern for local people or are they more concerned about the quality and timeliness of the service they receive?

Or

- Are waiting times the greatest concern for people or are they more worried about the quality of service and whether the service they received directly improved their health and wellbeing?

Keeping an open mind on this will impact on how you frame your questions to participants and how you analyse their responses – for example if you just ask about waiting times and only look for responses directly related to them, you will miss anything else people want to say or are talking about with regard to the quality of experience.

Who do you want to influence?

Before getting started it is also crucial that local Healthwatch are clear about which part of the system they are seeking to influence. Who will the result of the investigation be for:

- Is it for the Manager of a service?
- Is it for commissioners?
- Is it for the Board or chief executive of the organisation?
- Is it for the Health and Wellbeing Board or the Council Overview and Scrutiny Committee?
- Is it for the public?

Once these key decision makers have been identified it is important for local Healthwatch to consider what relationship it wishes to have with them. For example:

- Will they be asked for help with contacting people who have used the service, their staff and volunteers?
- Will any issues raised by the investigation be taken directly to them for a sense check before it is written up?

- Will they receive a draft of the report for comment?
- Does Healthwatch want an on-going relationship with them to keep track of the issue in the future?

What are you trying to find out, what questions are you seeking answers to?

It is easy to miss this stage out, but it is important to be clear about what the focus of the investigation is and what questions need answers to.

Without this clarity it is all too easy to ask too much and to end up with a mass of data which you are not sure what to do with, but at the same time not to have really got down to the main issue(s) of concern. It is usually helpful to have an overall aim and then a few more specific questions you are exploring. For example:

The overall aim of the investigation is to assess the public's level of satisfaction with the organisation of outpatient clinics in X department. Specifically you want to find out from patients/carers:

- Were they given sufficient flexibility around appointment dates/times?
- What was their experience of accessing the clinic?
- What was their experience of waiting to be seen?

There may be many further specifics that you want to explore within these questions, the trick is to keep them focused enough to stop the investigation straying into unrelated areas, but broad enough not to pre-determine what is important - leaving this open for respondents to decide.

For example the focus of the first area of investigation in the example above, is around 'flexibility' not pre-determined views of what Government may see as important, for example 'choice' or waiting times (see earlier points).

Be careful not to assume that patients and the public will understand or interpret issues in the way those working within health and care may do. In an increasingly complex system there is probably little point in asking people to reflect on a change in service providers for example – they may well be unaware of the change. Whether the change has made a difference can still be assessed, but for example by reference to change over a particular period of time.

Deciding on your approach and what methods to use

Local Healthwatch investigations often rely on questionnaires to members of the public. This can be one of the most appropriate ways of capturing experience and opinion but it is not the only mechanism available to local Healthwatch. The methods available fall broadly into four categories:

- Desk top research
 - o Policy Context - usually through government websites (guidance is more useful than the original policy), and comment by relevant specialist think tanks and national voluntary organisations
 - o Good practice guidance - usually produced by key regulators (eg CQC or NICE) and specialist national voluntary organisations or think tanks
 - o Reports that have analysed this type of service or the specific service under investigation - these could be national or local
 - o Existing data held by the provider, commissioner or regulator or key data collection agencies - these could include government departments, or specific bodies such as Public Health England or the Health and Social Care Information Centre. Locally this may include the Clinical Commissioning Group Quality and Outcomes Report and Quality Accounts and Local Accounts. Data and could include surveys, outcome statistics, service utilisation data etc.
- Seeking people's individual views via questionnaires/surveys which can be conducted remotely (by post or electronically), by telephone, or face to face
- Seeking people's views in a group – either group interviews, discussion or focus groups
- Observation – usually non participatory ie where the investigator observes what is going on in for example a waiting area, but does not take part in anything happening there.

Which method or combination of methods you decide to use should be determined by:

- Resources (in particularly people's time)
- Expertise (do you have anyone with the skills to run a focus group?)
- What you are trying to find out and what is appropriate. The latter will depend on who you want to gather intelligence from – your population group in research terms – and their characteristics. For example if the majority are unlikely to read or write English, then clearly an electronic survey is inappropriate – you will need to speak to them face to face, in their first language where needed.

What you are trying to find out is also key to deciding on methods. So for example finding out about people's experience of waiting could at least in part be done by an investigator observing – they could for example get a better idea of whether there was enough seating for the duration of the clinic than any individual patient would be able to give.

Whatever methods you decide on time must be spent in carefully designing and piloting them.

A poorly designed questionnaire will not yield responses that are much help in answering your questions and will be a nightmare to analyse. Equally a poorly planned and facilitated focus group could lead to one person dominating and fail to reflect the views of the group.

Whether you go for getting opinions from as many people as possible or focusing down on a few will depend very much on what you want to achieve. It can often be useful to do a combination – so that you can report some simple statistics based on a broadly representative sample, but also give some more detailed views to illustrate these from a few people that you have talked to in more

depth. There are many tried and tested ways of seeking people's views in questionnaires beyond simply asking questions – these include using scales and inviting people to agree/disagree with statements.

Generally speaking 'free texts' should be used with caution in questionnaires. They are often included in order to give people chance to say what they want to say in their own words, but whilst an element of this is useful, if you are conducting a large scale survey then it is better to give people a range of carefully worded choices.

Arguably this gives you a clearer idea of that respondent's views than if you are trying to interpret free text and code it in order to include it in the analysis.

Technique	Must Do/have	Advantages	Disadvantages
Large Scale structured Questionnaire	<ul style="list-style-type: none"> - Postcode information - Able to enter electronically - Analytical expertise - Focus on yes/no, scales, and multiple choice, limited free text 	<ul style="list-style-type: none"> - Population Level views - Can provide clear answers to broad questions - Allows for testing against inequality, diversity, geography 	<ul style="list-style-type: none"> - Important that questions are clear and focused. - Risk of too many overlapping questions - Requires analytical time and expertise - Limited in providing depth of understanding
Small scale semi-structured questionnaires or interviews	<ul style="list-style-type: none"> - Interviewer must be trained in taking member of public through questionnaire - schedule needs to be carefully designed - All interviewers must have clear identification 	<ul style="list-style-type: none"> - Provides an opportunity for personal experience to be heard - May reveal issues that were not considered when the questionnaire was designed 	<ul style="list-style-type: none"> - Not population level - provides a perspective or insight which helps develop understanding
Focus Group	<ul style="list-style-type: none"> - Skilled facilitator who can ensure participation, test ideas, capture and record the discussion 	<ul style="list-style-type: none"> - Can allow ideas to develop helping participants remember experiences and validate experiences 	<ul style="list-style-type: none"> - Risk of being dominated by a small number of individuals who group members are reluctant to disagree with
Observation	<ul style="list-style-type: none"> - Observer should be trained and have a clear focus. - Need to cover varied opening hours of service - Day time, weekend, evenings etc. 	<ul style="list-style-type: none"> - Gives a feeling for the flow of the service, how it changes at different times of the day 	<ul style="list-style-type: none"> - Does not get the views of users or staff.

Making a Plan!

Once you have decided on which methods you are going to use then it is time to make a plan which clearly sets out who will do what and by when. It should include:

- how you will recruit participants and any selection criteria (over 18, mental capacity, able to speak English etc.),
- who will design questionnaires, interview schedules, observation checklists etc and by when
- where and when data collection will take place
- who will do the data collection and what sort of briefing/training they need
- how information will be recorded and data entered, by whom and by what date
- how this data will be analysed (e.g. what packages will be used?) by whom and by when
- Who will write up the report, who will check it, and by when.

Going into action!

You will notice that this is the shortest section of this briefing. If you have done your preparation, then actually undertaking the investigation will hopefully happen as and when planned. However there are always unanticipated issues and things rarely work out quite you intended. So your investigation team need to be available to sort out any glitches through this period and to modify and adjust plans as you go. It is worth doing a risk assessment before you start the investigation so that you have anticipated any areas where things could go wrong and have a back-up plan.

Making sense of the data you have gathered

Too many investigations run out of steam at the analysis stage and this is rushed or worse still, never done and survey forms pile up in cupboards and focus group transcripts remain on digi recorders!

Use of survey monkey or similar packages has the great advantage that some analysis is done for you at the click of mouse. However this will be limited and if you want a more in depth analysis you will need to consider either paying for the more sophisticated versions of these packages or accessing a package like SPSS² which will enable you to do far more in the way of cross tabulation and analysis. SPSS of course has a cost and you need to have team members who can use it – this maybe where a partnership with a University could be helpful.

There is also a package called Geoconvert which converts postcode information into super output areas which enables analysis by deprivation. To use this you need to collect full postcodes from respondents – it then enables the investigator to analyse for example, whether respondents from areas of deprivation have the same or different views/experiences from the group as a whole, something which will be of importance to local Healthwatch seeking to address inequalities in experience of health care. Again, Geoconvert has to be paid for and staff need to know how to use it, so a collaboration with a University or other partner agency that has it would be useful.

Analysing qualitative data can be equally challenging. How on earth do you make sense of all that free text data or discussion group notes or transcripts? Basically you have to go through it and

² Statistical Package for the Social Sciences

'code' it – ie decide on things that seem to keep recurring in the text, give them a name or code (eg 'not enough seating in waiting area' and 'uncomfortable seating') and then group these together to come up with main themes that are emerging (eg 'seating'). You will have to make decisions about what comments mean and decide how to weight them (the data does not 'speak for itself') so it is important that more than one person is involved in analysis. Be careful not to draw conclusions from one or two comments and to use quotations to support an emerging theme, not because they are catchy.

Then you need to take a step back (literally have a day away from the data if possible) before you decide what the headline messages are. You have been immersed in the trees but now you need to stand away from them a bit and have a look at the wood! You also need to look back at your context and interpret what you have found against any good practice standards, national or local policy and any relevant reports into the issue/service.

Writing up

We have talked about the importance of knowing who you are seeking to influence and making sure your investigation and report reflects their concerns and areas of responsibility. But it is also important to write reports which are accessible to the public. This can be challenging and on occasion you might decide to write a short summary report for wide circulation and a more detailed one for service providers and commissioners, but generally it is preferable to stick to one report which is:

- Written in plain English
- Reasonably brief and to the point, whilst still providing enough detail - don't forget the people you are trying to influence need to have grasped the purpose of the investigation, why you did it, what you found out and what your recommendations are in the first 3 or 4 minutes of reading. All of the rest of the information is to back up these points.
- Contains a summary of key findings at beginning
- Provides detail on for example methods and investigation plan in appendices or separate documents available on request (they will clutter up main report but need to be there for reference).
- Clearly states main findings and how these measure up against practice standards/policy
- Has recommendations re what needs to happen next – these will not detail what managers need to do to address the issues raised (that is for them to determine with patient/public input), but will say who needs to take action and in what timescale
- Sometimes you will not feel in a position to make a recommendation but may wish to flag up areas that might merit from 'further investigation' or that 'might need to be returned to in 6 months.'
- Suggests a process for review and progress checking

Local Healthwatch may find it useful to consider whether they need to produce different sorts of reports and to agree a standard approach to these. Whilst one person needs to be nominated as main author it is important to have a process of quality checking before any report is shared. If comments are being invited from managers/commissioners pre-publication, there has to be clear

deadlines for this. Ultimately local Healthwatch have to feel confident that reports are credible and that they can defend the way the investigation was conducted and the conclusions reached.

Conclusion

This briefing is based on the experiences and learning of local Healthwatch in Yorkshire and Humber explores ways forward. However 'intelligence gathering' is a huge area and detailed exploration of the process has not been possible in a short briefing. What we hope we have done is highlighted the key areas where local Healthwatch can learn from research practice in order to make their intelligence gathering as rigorous and credible as possible.

Acknowledgements

We would like to thank the following local Healthwatch in particular - Healthwatch Leeds, Healthwatch Wakefield, Healthwatch Calderdale, Healthwatch Bradford, Healthwatch Kirklees. As we note this report is based on their experiences and practice.

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