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MEASURING THE IMPACT OF HEALTH TRAINERS SERVICES ON HEALTH AND HEALTH INEQUALITIES: DOES THE SERVICE'S DATA COLLECTION AND REPORTING SYSTEM (DCRS) PROVIDE RELIABLE INFORMATION?

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ABSTRACT

Background

The Health Trainers Service is one of the few public health policies where a bespoke database—the Data Collection and Reporting System (DCRS) — was developed to monitor performance. We seek to understand the context within which local services and staff have used the DCRS and to consider how this might influence interpretation of collected data.

Methods

In-depth case studies of six local services purposively sampled to represent the range of service provider arrangements, including detailed interviews with key stakeholders (n=118).

Results

Capturing detailed information on activity with clients was alien to many Health Trainers' work practices. This related to technical challenges but it also ran counter to beliefs as to how a 'lay' service would operate. Interviewees noted the inadequacy of the dataset to capture all client impacts; that is, it did not enable them to input information about issues a client living in a deprived neighbourhood might experience and seek help to address.

Conclusion

The utility of the DCRS may be compromised both by incomplete ascertainment of activity and by incorrect data inputted by some Health Trainers. The DCRS is also under-estimate the effectiveness of work Health Trainers have undertaken to address 'upstream' factors affecting client health

INTRODUCTION

In the Public Health White Paper *Choosing Health* [1], Health Trainers were introduced as a new member of the NHS workforce; a resource so that *'everyone who wants will also be able to access personalised advice from Health Trainers, properly and professionally trained, and accredited by the NHS'* (para. 9). Health Trainers were to be recruited from local communities, and were promised to be *'friendly, approachable, understanding and supportive ... They will be people who are in touch with the realities of the lives of the people with whom they work and connected through a shared stake in improving the health of the communities that they live in' (para. 11). Although eventually to be a universal service, Health Trainer services were first implemented in the 20% of (then) PCTs with the worst health and deprivation indices ('Spearhead' areas).*

One of the challenges in measuring the impact of complex public health interventions is the lack of routinely-available data which captures sufficiently specific information on the outcomes among the targeted population. However, and in contrast to many other policies, implementation of the Health Trainer Service (HTS) was accompanied by the development of a bespoke database – the Data Collection and Reporting System (DCRS) – which captured information not only on processes and outputs, but also on short-term outcome measures. Published analyses of DCRS have suggested that these data offer evidence that the HTS has the potential to improve population health and reduce health inequalities [2-4]. In this paper, we seek to understand the context within which local services and staff have used the DCRS and to consider how this might influence interpretation of data analyses.

METHODS

In 2008 we were awarded funding to undertake a review of the national implementation of the HTS in England. We were given access to national policy and project management documents and to national activity reports. We also undertook in-depth longitudinal case studies of six local services.

The Data Collection and Reporting System (DCRS)

The origins of a national data collection system lay in early recognition by the team at the Department of Health tasked with implementing the HTS policy that the service would need to

demonstrate its value to the NHS. Accordingly, in January 2007 the Centre for Outcomes Research and Effectiveness at University College London were asked to produce the first National Health Trainer Activity Report. Data collection relied upon paper-based audit sheets compiled by the lead of each local service and returned to the UCL team. In the Briefing Note summarising the key findings from the report, the challenge of relying on retrospective paper-based data records was noted, and went on to advise 'it is essential that accurate, valid and reliable quantitative process and outcomes data are now collected across services. This will be facilitated by universal adoption of the National Health Trainer Data Collection System and the mandatory collection of a core or minimum dataset' [5].

The new National Health Trainer Data Collection System was based upon an existing Data Collection Reporting System (DCRS) already in use by the (then) Birmingham Primary Care Shared Services Agency as a performance management tool for the West Midlands Health Trainers Hub. The DCRS was available on-line for services and their Health Trainers to input simple workforce (e.g. number of trainers, hours worked, number of clients seen) and client information (name, postcode, how they came to know about the service) within the West Midlands from October 2006 onwards. By 2009 the DCRS minimum dataset had been expanded substantially to capture a range of information on client behaviours (for example questions on diet, smoking, exercise and alcohol use) and on the agreed goals set by the client with their Health Trainer set out in their Personal Health Plan (PHP). The most recent report available to us when undertaking our fieldwork provided information up until the end of the 2011/12 financial year [6]. It is this report from which the data presented in this paper is taken.

In-Depth Case Studies of Health Trainer Services

The case study services (A-E) were purposively sampled to include a range of HTS provider arrangements (NHS, Third Sector Organisations), geographical locations (urban, urban/rural), and populations served. We also included one case study where a service had not been established (F).

Tailored in-depth interviews (n=118) conducted with stakeholders sampled via purposive and snowballing techniques (service co-ordinators, Health Trainers, Directors of Public Health (DsPH), commissioners, and staff in partner TSO providers) provided in-depth accounts of service establishment and development. A minimum of two visits were made to each service

and follow up interviews conducted. Initial visits took place in late 2009 / early 2010, with final follow up visits 12-18 months later.

Interviews were recorded with the consent of participants and transcribed *ad verbatim* for analysis. A thematic analysis of content was undertaken informed by the Framework analytical approach [7]. Following initial familiarisation, coding and thematic development proceeded iteratively via on-going discussion amongst the team. Analyses presented here focus on the comparative findings across individual case study services, including cross-case recurrent observations and themes.

RESULTS

The Reach of the HTS nationally

The first thing to note is that despite the DCRS being the mechanism by which the HTS is to be monitored, not all services report their activities to it with the most recent estimate suggesting only $^{\sim}60\%$ of services are using it [8].

By the end of the 2011/12 financial year, the DCRS Reports indicated the total number of new clients seen by HTS across England by the end of 2011/12 was 370,047 [6; p4]. Using the population estimates from the 2011 Census, this suggests that the HTSs have been accessed by ~0.8% the English adult population.

Over two-third of the clients were female (p12) with just over one-half (52.4%) of clients aged 26-55 years (vs 41.2% national population). Compared to the national population, clients were less likely to self-define themselves as White British (70.4% vs. 79.8%; p11) and more likely to be of Asian/British Asian origin (10.3% vs 5.5%). The most striking difference between the national population and client demographics was in regard to deprivation: Over two-thirds (68.1%) of clients were resident in areas categorised as being in the two most deprived quintiles with only 1 in 20 (5.4%) resident in areas belonging to the most affluent quintile.

The Effectiveness of the HTS nationally

Approximately 55% of all clients (n=201,517) who engaged with a local HTS went onto to agree a PHP of which just under one-quarter (n=87,180) were recorded as having been 'signed off 'by their Trainer (i.e. they completed their PHP)(p5). The majority of PHPs focused on diet (n=124,206; 61.6%) or exercise (n=44,739; 22.2%) (p5); less attention focused on alcohol (3,685; 1.8%) or smoking (15,968; 7.9%) possibly because other specialist services exist for these and to which Trainers would be encouraged to refer.

Outcome data were reported for varying sample sizes (~30,000-40,000 clients) suggesting these data were only available for a proportion of those who completed their PHP. Mean weight loss was 3.8kg (95.6kg vs 91.8kg; 3.97% reduction) with an average change in BMI of 1.4 kg/m² (35.1 to 33.7; 3.99% reduction). The data also indicated increases in daily fruit and vegetables consumption, and in the number of moderate and vigorous sessions of exercise undertaken each week.

PHP sign-off occurred at around 12 weeks after the plan was agree, thus the outcome data reported relatively short-term change. However, for a small subgroup of patients (n=20,420) data from 'maintenance checks' where a Health Trainer has contacted the client some 3-6 months after sign-off to ascertain progress was available. Among those who completed their plan, 86.5% reported maintaining their behaviour change.

Finally, the DCRS captured measures of more general well-being using three measures (self-efficacy, general health, and WHO-5 Well-being). Data was only available for a subset of \sim 10% of clients with before-and-after comparisons, but it suggested a marked improvement in all three measures (p19). When outcomes were stratified by the focus of the PHP, it was notable that 'local issues' shows the greatest magnitude of change (p19) – i.e. those presenting with local issues seem to have greatest improvement (see Discussion).

How DCRS is used and experienced by local services and staff

In this section we use data collected from the case study services to understand how the DCRS was used in 'real life'. In short, we observed that capturing detailed information on activity with clients was alien to many Health Trainers' work practices. In part this related to the technical challenge of using an online data collection system, but also it ran counter to how a 'person next

door' would provide support to their 'neighbour'. The introduction of the psychological measures – while valid in terms of theories underpinning behavioural change – and the manner in which the questions were framed was especially problematic for some Health Trainers and their clients. Where Health Trainers did get to grips with the DCRS, a frequent complaint was the inadequacy of the dataset to capture the totality of their impact on clients; that is, DCRS was not set up to able to enable them to input information about issues a client living in a deprived neighbourhood might experience and seek help to address. These issues are now discussed further.

The DCRS was introduced at different time points within case studies with some of the services up-and-running before the roll-out of DCRS. For services where Health Trainers had not routinely recorded significant amounts of monitoring data from service start-up they had to accommodate the new data requirements of the EPMSG and implement processes to record, collate and input data. For some Health Trainers this was not a smooth, nor welcomed transition, as one manager noted:

"....because the nature of the Health Trainers, they're not health professionals. They're barmaids, they're cleaners, they're labourers, they're this, that and the other. They're not IT savvy, and that's part of the ethos of the Health Trainers which, in a way is fabulous, but it also means that IT skills aren't so much up to date and there's a lot of confidence issues around it so we ... I've had to introduce that all softly, softly, to get them used to this DCRS system which they are beginning to, and I am so proud of them because they're all beginning to input onto it. And I know they're not confident but we've done training after training and e-mails after e-mails making sure they're okay and bringing them back in. And I have to say they don't particularly like it but I keep saying in six months time it's another skill that you've got and you will be flying..." (Interviewee 54)

Where services worked in partnership with non-NHS organisations (most usually TSOs), an additional challenge was one of inculcating the 'performance management' and 'monitoring' mindset of the NHS to these partner organisations.

"But, to be honest, we were struggling with the third sector providers in the beginning to even capture anything. It just wasn't in their normal remit to write things down when they saw people. So it took quite a long time to get any sort of reporting at all, really. But that was part of the social capital building, part of the building of the third sector agencies, which we felt was valuable in its own right." (Interviewee 1)

"I know certainly that both voluntary sector providers found the database quite challenging to use and they couldn't follow how it operated and they just felt like it was something that they fell into and didn't get any information back out, you know, but wasn't like useful for them in

terms of managing the service. I think they just didn't really appreciate perhaps the importance of recording what they did." (Interviewee 14)

One of the major concerns expressed by Health Trainers was that data collection risked changing the nature of their interactions with clients. Some Health Trainers also voiced concerns about the negative connotations of completing paperwork for some target clients, including suspicions about what the data will be used for. Others went on to talk of excusing the need to ask certain questions and collect certain data with clients, so getting the data collection out of the way and enabling them to concentrate on how they would prefer to work with people – see, for example, comments from Interviewees 76:

"because I like to talk to the person, looking at them straight in the face and in the eye because if someone spoke to me, like that, I'd go mad. Just looking at the paper, or not even looking at me because we're supposed to take our little laptops out and do it on the laptop but it freezes, it does this, does that and the connections are not really good. You're taking that one-to-one and that's the way we're supposed to be working. We're taking that away from it." (Interviewee 76)

"Yeah, so I always put 'no' in there [points at the section for the name and address of the client's GP], - she's not even registered with a doctor. So when that comes back, they [people analysing DCRS outputs] all go 'God, no one in [names Service] is registered with a doctor'. [That's] because I can't be bothered wasting all that time. ... Some of the questions on it [the DCRS], they make me laugh: 'what would increase your confidence? Assured of a confidential service; being satisfied with progress; guaranteed support of family; overcoming fear of failure?' I'm talking to a client from the community and they go 'I don't know, what are you on about, what does that mean?' 'My support helping you' 'oh yeah go on then, tick that box then yeah'. They only want to lose weight." (Interviewee 76)

Others also criticised the 'meaning' of some of the questions soliciting information on the psychological measures, and also the validity of answers given to questions about lifestyle and behaviour.

"So we've got forms that assess their self efficacy...... How ready they are for change and things like that, so their motivations which are the most awful bits of paperwork I've ever seen in my life. They don't relate to a client, they don't even make sense most of them. Yeah you've got all these really long winded stupid questions as far as I'm concerned. Then you've got answers like 'all of the time', 'some of the time', 'often', 'not very often', things like that. And they're just sat there going "What? What are you talking about?" (Interviewee 27)

"some information about whether you exercise, what you eat, what you drink, do you smoke. And to be honest, very few people fill these in accurately. I had a woman recently from [names area], she's 23 stone, and if you'd seen what she did exercise wise and what food she ate, you would wonder who put the extra 15 stone on her like..." (Interviewee 42)

The DCRS was also thought to be inadequate in capturing and demonstrating the impacts that Health Trainers were achieving with clients. Here, interviewees identified a lack of accommodation of broader impacts on social and psychosocial determinants in the DCRS, areas where they felt services were having substantial effect. This included criticism of the ability to record impact on factors such as reducing social isolation, or assisting s client get a job or decent housing, despite the provision of self-efficacy and well-being measures in the dataset.

"Interviewer: So what would you have filled in for that then on the DCRS?

Interviewee: It's stupid, it'll just look as though this client needed to put weight on but the whole lifestyle thing around her and she was in debt up to her eyes. So I got a couple of forms for her to fill in for the Credit Union. So she's in that and she's started saving up, she's got a new flat now because she's come out, she had a private landlord who was threatening her and she had gangsters threatening her and she had the robbers come in and rob it all off her. Now she owes them all kinds of money so we've got her out of the area and stuff like that. Where's the box I can tick for that, so it's not capturing things here." (Interviewee 76)

In relation to this, interviewees questioned the ability of the DCRS to show the added value of the impacts described by Health Trainers:

"He came to see me, 23 and he'd got a 52 BMI...... I was lucky he'd actually come out of the house because he'd stopped coming out the house. He was referred by his GP. Came and saw me at the doctor's surgery. Played all night on the computer. Sat with pizzas, whatever. Had bouts of mild depression. But a very angry man, a very angry young man. Didn't do a lot. I'm trying to think when I first saw him. It was probably about June as well. September his weight loss was, for his size, he'd lost about 10lbs, so for his size not really...visually you couldn't tell, he couldn't tell on his clothes. Because 10lbs on that sort of size you're not going to see. But he had actually achieved some weight loss. But he'd started college, he was going to bed at a decent time, he was eating meals to regular times. And that was all down to his confidence he'd felt from sitting and talking to me. But on the database nobody sees that. That's not measured. That's not measured that you've actually got somebody to actually reassess their life and put themselves back into society and think they're worth something. And I find that extremely frustrating. Because that's not measured, there's nowhere to...and that's not for me to think that I've got nobody up there saying well done ... for me just seeing that in somebody is satisfaction itself. But as a service, and that's not just an isolated case, that is we all must have at least I'd say two or three in our caseloads that they're never going to be measured as a...do you know what I mean?" (Interviewee 89)

DISCUSSION

Main findings

Data collected by the DCRS is increasingly being used to describe and analyse the impact of the HTS. However in this paper, we have suggested that the DCRS is compromised both by incomplete ascertainment of activity and by incorrect / missing data inputting by some Health Trainers – either deliberately or indirectly where they record client self-reported behaviours despite reservations as to the reliability of these. The DCRS is also unable to capture the totality of the impact the Health Trainers have with some clients.

What is already known on this topic

Our reporting of the DCRS data echoes the findings of others who have interrogated the DCRS directly and undertaken more sophisticated analyses to explore predictors of behavioural change. For example, Gardner and colleagues observed among first-time users of the HTS in the period 01/04/08 to 31/03/09 (n=27,670), 4418 clients (16%) set goals relating to diet or exercise and had outcome data suggesting a change in BMI of 1.77kg/m² [3].

What this study adds

We would concur with Gardner et al's observations that there are a number of issues apparent in the DCRS including incomplete client ascertainment, the reliance on self-reported measures of behaviour and an absence of longer-term follow-up data, which necessitate great caution in interpreting these data [3]. However our point of departure would be with their comment that "we have no reason to suspect that clients or HTs are unwilling to provide data. Rather, missing data problems may stem from organisational variations in the history of each service, levels of support from local Primary Care Trusts and the commitment of local HTS managers to collecting and recording behavioural change and related data within a centralised and standardised database" (p1190). We agree that these elements are important, but we believe there are also some inherent errors in the information held on DCRS which relate to the Health Trainers and their clients. Underpinning these errors is the dissonance between the need to collect data on outcomes deemed relevant by the policy-makers, and the perceptions of Health Trainers as to the purpose of the service and what is 'important' to clients. Modification of the DCRS overtime has seen the introduction of a 'Local Issue' category for problems not fitting into smoking,

alcohol, diet and exercise but in itself this is inadequate to capture the activity undertaken by a Health Trainer as a necessary precursor to engagement to change disadvantaged clients' health-related behaviours; for example working within the community to raise awareness of the service, or with individual clients addressing more 'upstream' problems (e.g. debt, domestic violence) which necessitated resolution prior to considering lifestyle change. It is interesting here to note that the National Implementation Team although continuing to advocate use of DCRS, also developed their own 'story books' – collections of client and Health Trainer 'stories' as to how the HTS has helped and brought about change to their lives [9].

Limitations

Our observations are based on work undertaken with a series of staff working in or with selected case study services. These services were purposively identified so as to capture the range of HTS characteristics but it is possible that they are not representative of the totality of the services contributing to the DCRS. In a similar manner, interviewees may not be 'typical' of the wider Health Trainer workforce. Our fieldwork was undertaken during the early years of the HTS and over time we perceived some services to move away from prioritising the recruitment of 'people next door' towards the employment of more 'work ready' staff – an observation supported by the most recent DCRS Report which suggests one-third of Health Trainers are university graduates [8; p14]. It is possible that the experiences we report here do not reflect those of more recently recruited staff.

CONCLUSION

Much hard work was been done to establish the HTS and many of the DCRS's process measures suggest the HTS has punched above its weight in engaging with large numbers of clients disproportionately coming from the most deprived backgrounds. However, the extent to which the reported outcomes can be extrapolated to population health gain is unclear and caution is needed when interpreting these data. Despite this, we would stress that our conclusions are not that HTS has 'not worked'. Rather we would argue that the DCRS has 'not worked'. Our own experiences of working with services have surfaced Health Trainer narratives which consistently present stories of clients where interaction with the local service appears to have instigated quite fundamental and life-changing processes [10] - an observation noted by others

[11-13]. The Health Trainers attribute these successes to the characteristics of their relationship with the clients (sustained, peer, intensive, collaborative) and contrast it with the types of interactions likely to occur with other healthcare services and healthcare professionals – characteristics typical of other community health workers and services [14]. We believe that the DCRS can only capture a small part of the impact of this relationship.

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