Final report

February 2017

Innovating for Improvement

Using technology and an evidence-based, outcome-led approach to reduce health inequalities for people with learning disabilities

Hft

The Health Foundation

About the project

Project title: Using technology and an evidence-based, outcome-led approach to reduce health inequalities for people with learning disabilities.

Lead organisation: Hft

Partner organisation: Rescon Technologies

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Part 1: Abstract

People with learning disabilities are living longer than earlier generations but are more likely to develop long-term conditions at an earlier age, as well as experiencing inequitable health outcomes compared with the general population with equivalent health needs. Health issues in people with learning disabilities can be overlooked or misunderstood due to difficulties in communicating (or staff understanding of) their feelings. These barriers can prevent diagnosis, delay treatment, reduce wellbeing and exacerbate existing conditions and may lead to premature death.

Hft devised a project, led by its Personalised Technology (PT) team, to improve communication between people with learning disabilities, health practitioners and support staff, and to gather insights into care quality in order to reduce health inequalities. The project brought together two tools: Lincus, an easy-to-use picture and simple word-based application for recording health and wellbeing information; and the Health Equalities Framework (HEF), an evidence-based outcomes framework which gives a snapshot of the health inequalities that a person is experiencing.

Using Lincus and HEF can enhance communication and insight between practitioners and people with learning disabilities by allowing both parties to gain more information into how the person is feeling and their current health needs and factors contributing to the risk of serious health inequalities in future. The system was piloted with two groups of around 20 people very different needs and in contrasting settings: a residential care service in semi-rural Gloucestershire and a day-service in Bradford city centre.

Image 1: a person we support in Gloucestershire using Lincus.

It was hoped that integrating these platforms would enable Hft to develop a practical, user friendly tool that supports people with learning disabilities to take control of their health care and manage any long-term conditions, whilst guiding and supporting staff to improve care quality.

The evidence and insights generated by these tools have the potential to change

care pathways for people with learning disabilities in a way that has never previously been realised.

Narrative account

The project was managed by Hft's Innovation Manager. The core project team was identified at the application stage and finalised at a project kick-off meeting. Hft's existing Health and Wellbeing group (a group of trustees, staff, GPs, consultants and technologists tasked with looking at the impact of health and wellbeing on the population supported by Hft) was identified as the Project Review Group. One of the HEF's original authors was invited to join this group for the duration of the project. The Operations leads in Bradford and Gloucestershire identified two existing stakeholder groups within their areas to act as Project Advisory Groups. These groups included local clinicians, commissioners and service users.

Regular update reports (in the form of a bi-weekly conference call) were set-up with the core project team and regular site visits from the PT team took place.
Training in usage of HEF and Lincus was provided in-house, by the Hft PT team and HEF author, and the necessary hardware provided. The specific aims and objectives of each of the project sites were deliberately left open. This was in part due to the differing nature of the two services – i.e. day services versus residential care and the differing regulatory frameworks and staff roles and responsibilities. It is also in-keeping with Hft's person-centred approach to supporting individuals and a desire to focus staff interventions on areas that would have the most impact and meaning for each individual.

> Having that historical data, as well as the up to date data, helps you to understand the individual much better.
>
> Personalised Technology Coordinator, Hft

Baseline HEF assessments were conducted and regular Lincus usage began. The technical structure of the Lincus platform enable results to be collated and analysed on an ongoing basis. An evaluation partner, the Bayswater Institute (BI) was also identified and commissioned to produce a report on the project. BI met with both operations teams several times and attended several project review group meetings to scope out the report and analyse the issues and opportunities.

One of the main challenges in the project, and specifically in evaluating it, was answering the question: what does success look like? Any evaluation of the project needed to take into account:

- How to meaningfully evaluate qualitative outcomes for a group of individuals with differing needs;
- The quantitative outcome on the impact on resources, both for Hft as a social care provider and for other stakeholders across the wider health and social care economy, all of whom have different budgets and remits for care.

This must also be considered in the context of commissioning in England, which is focused on outputs and processes (such as number of hours of support required) rather the outcomes for individuals.

It was also necessary at this stage to carefully consider data governance and who should have access to what type of data and in what level of detail.

Testing the intervention

To test the intervention, we worked with Operations staff to identify a suitable target population, working with them to identify individuals who would benefit most. It was also agreed how and when the HEF would be used: baseline profiles were to be generated at the start of the project and repeated after six months, as a minimum. We also stipulated a minimum usage level for Lincus (once per week); however this was very much down to individual needs and preferences. Progress was monitored via bi-weekly conference calls, which also allowed the two pilot sites to learn from each other's experiences. In effect, this established a virtual community of practice by which the different sites could learn from experiences of introducing the Lincus surveys and the HEF; and also in relation to how care and support was aligned to the data that began to flow from the tools.

What went well

The usage of the system in Bradford went particularly well. The staff team selected had strong existing relationships with Primary Care, as well as therapists and other health professionals. The team were able to use these relationships to their advantage in progressing the project outside Hft and meant that the insights gained through the HEF and Lincus were shared, welcomed and influenced their practice too. The Bradford team completed an interim, second HEF assessment in May 2016 to monitor their own progress.

> The HEF makes you look in depth at the person's health and it makes you question the things that most of us take for granted.
>
> Learning Disability Nurse, Bradford

Initially they were concerned that the HEF scores may have worsened. In actual fact scores did slightly improve and actually served to demonstrate how much more information about people's health and wellbeing we now have and means we can work to improve both people's health and wellbeing and the systems currently in place. (In keeping with these discoveries, some of the HEF indicator scores did increase.) One of the key impacts of the project is that social care staff within Hft now better understand the impact of social factors of health and wellbeing; staff have a clearer understanding of what can be done to reduce health inequalities and support systems have been refined to promote improvements in health and wellbeing.

The personal and professional relationships and partnerships that began and were developed within the project became one of its key strengths. This included developing strong working relationships between teams in Hft, as well as an external commercial relationship that has been developed between the creators of HEF and Lincus and ongoing work with members of the project review group.

The project also appears to have sparked a great interest in HEF and Lincus in other Hft services (and further afield) to support evidence-based, outcome measurement.

Addressing the challenges

The only major challenge we have faced was related to project delivery in the Gloucestershire site. Despite the onsite manager (and member of the Health and Wellbeing group) requesting to be part of the project and being very supportive, the commitment to the project from other staff members was limited. This was largely due to external pressures on staff and recruitment issues which resulted in a reliance on temporary staff, as well as a large house-move project for the people we support. This lack of commitment to the project resulted in a delay in completing initial HEF assessments and a lack of regular usage of Lincus.

Initially this issue was addressed by working with the Hft specialist skills team to complete HEF assessments; secondly by assigning an onsite manager to lead Lincus usage; and finally, and successfully, a member of the PT team took on the project within the service and managed regular usage of Lincus. Although this situation initially presented a very serious and significant challenge to the success of the project, the outcome has actually been positive overall and has produced some encouraging results.

Whilst in its original format, the HEF is free to use and share, its licensing protects the IP of its authors by prohibiting the development of derivative products, or its use for commercial gain, by third parties. Therefore permission needed to be sought to embed the HEF within Lincus. After initial discussions, permission was granted, free of charge, for the purposes and lifetime of the project.

Outcomes and the impact

The overall outcomes in the Bradford service were:

- Support plans have changed and now have a section called a Health Plan and new topics have been added to reflect the work we have done and to ensure that care and support has a greater focus on reducing health inequalities.
- Transition plans have now evolved to address what information is needed prior to someone joining the day service and what needs to be reviewed and updated before a placement starts. This ensures better coordination and continuity at time of significant life change for the people we support.
- Not making assumptions about a family or carer's knowledge base around health. Health issues are now more fully discussed at regular reviews.
- The day service now acts as a service that will sign post and refer to health, working with health to provide a better service and better outcomes for people with learning disabilities.

> The key thing for us, working with people with learning disabilities, is to gauge as much information as we can so we can fit them more than they fit our service.
>
> Operations and Quality Manager, Hft Bradford

Overall the outcomes in Gloucestershire were less clear but the project served to highlight the impact of suitable (or unsuitable) housing on people's exposure to health inequalities, as well as the impact of having increased choice to make unwise decisions, such as those relating to diet or alcohol consumption. This prompted an

exploration of issues relating to positive risk taking in accordance with peoples' preferences versus risk aversion, where people choose some aspects of an unhealthy lifestyle.

Summary of learnings

The way the project evolved over time created several key learnings:

There's more than one way to embed innovation.

What we planned to do was train the operations staff, introduce Lincus and HEF and then operations staff would engage with the people we support. This is what happened in Bradford: in effect, a 'top down' approach.

Due to the issues experienced in Gloucestershire, by introducing HEF and Lincus to the people we support via a member of the PT team, what happened was, over time, people we support began to ask regular staff to use Lincus following their work with the PT team: in effect, a 'bottom up' approach.

Where does the day service start and end?

In Bradford, the project gave us much greater knowledge about people's health and wellbeing; thus enabling us to identify where the gaps in support are and whether these gaps are nominally the responsibility of the day service or not. This raises the question about where the day service's responsibilities begin and end and forced us to consider the breadth and boundaries of our role in minimising the impact of determinants of health inequality.

There's a growing need to find out how we integrate health and social care, in terms of roles and responsibilities of the relevant staff.

Social care has a huge role to play in meeting the health and wellbeing needs of people with learning disabilities (and others). At present, the lack of integration between health and social care does not support this. Integration between health and social care for people with learning disabilities will become increasingly important, particularly as this population continues to age and develop poorer health.

Part 2: Progress and outcomes

Lincus is a holistic evaluation and care delivery platform which helps people communicate how they are feeling. Using Lincus, people can track health and wellbeing, events and interventions to provide personal and shared insight on what works best to improve wellbeing. Prior to this project, Hft had worked with Rescon (creators of Lincus) to develop a learning disability specific version of Lincus which is largely graphic-based with a few simple words. This user-centred design approach continued throughout project.

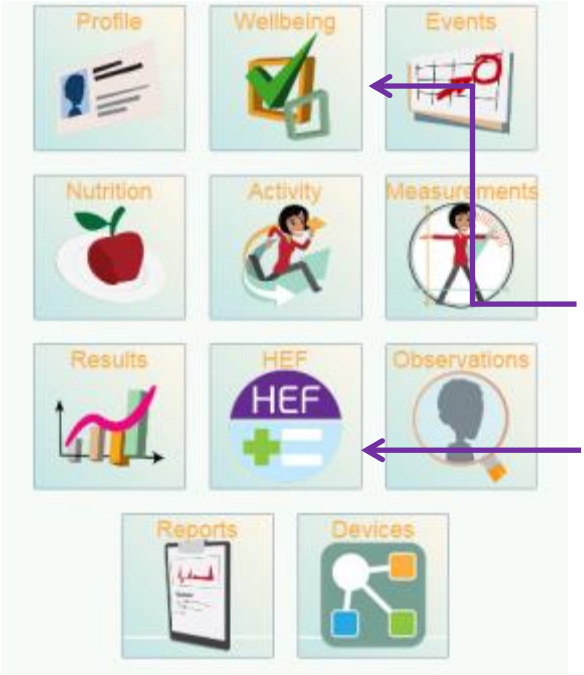


Figure 1.

Figure 1 shows the home screen of the Lincus platform and the number of modules available.

The modules we have mainly been using are: Wellbeing, which consists of four surveys: General Health (figure 2), Social Life (figure 3), Emotional Health (figure 4) and Mental Health (figure 5).
HEF: the Health Equalities Framework.

Bradford also started exploring the use of measurements for certain individuals.

The four surveys each consist of a series of questions with a sliding scale for individuals to indicate how they are feeling. Over time this creates data that can be analysed and interrogated, including the impact of certain events and interventions on individuals.

Figure 2.

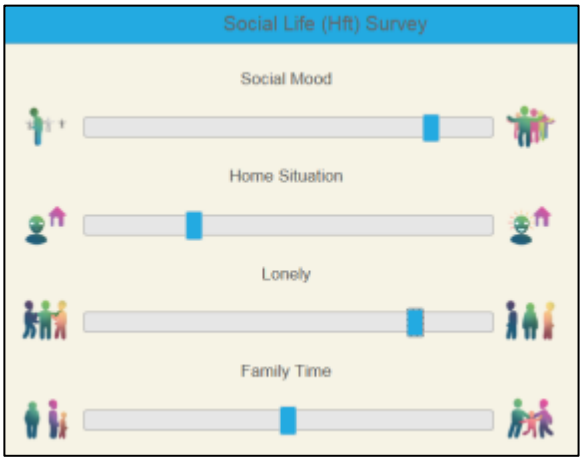


Figure 3.

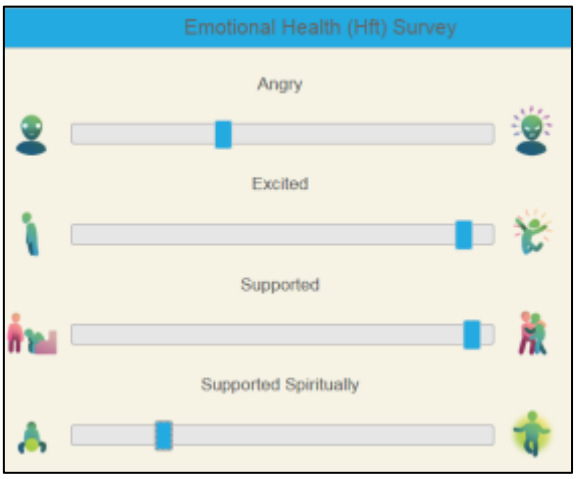


Figure 4.

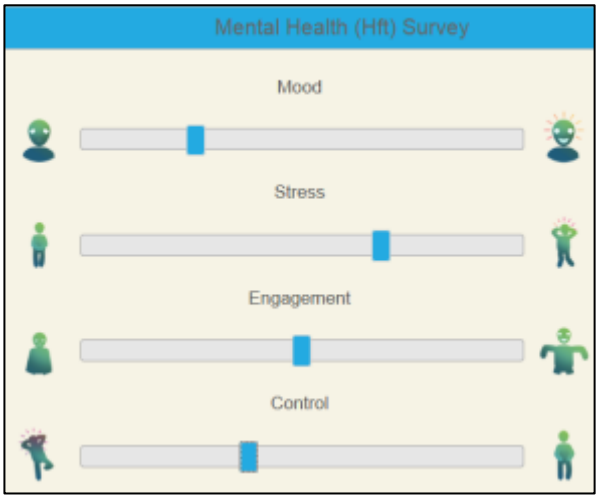


Figure 5.

HEF was initially created and disseminated as an Excel spreadsheet by which to measure the impact of service delivery in reducing the likelihood of people with learning disabilities experiencing serious health inequalities. It was created in response to a series of national reports and findings in this area, in particular the Panorama exposure of the treatment of residents at Winterbourne View. It is made up of 29 discrete indicators in five domains: social, genetic and biological, communication, behaviour and lifestyle and service quality. Once an assessment is made, a 'guiding star' is created (figure 6). This allows users to identify where there is significant exposure to the determinants of health inequality and guides them to

put into place mitigation strategies or activities to reduce health inequalities where possible. The guiding star also allows for visual comparisons between two HEF profiles to be made easily. The higher the score (indicated red), the greater the exposure to determinants of health inequalities.

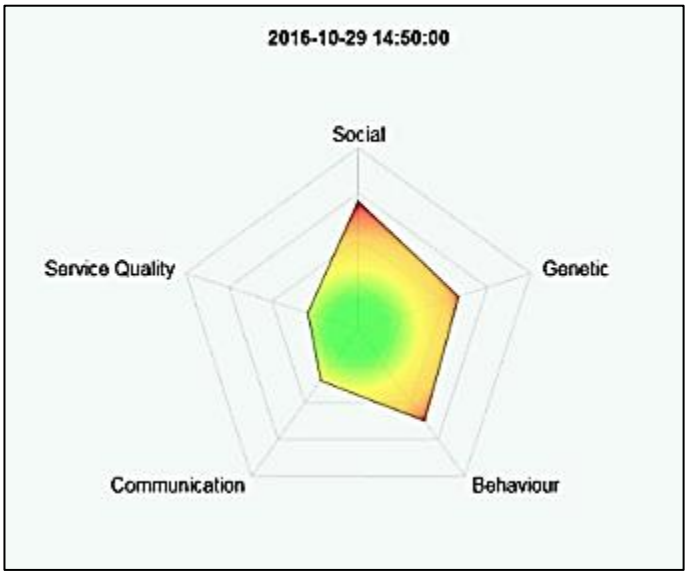
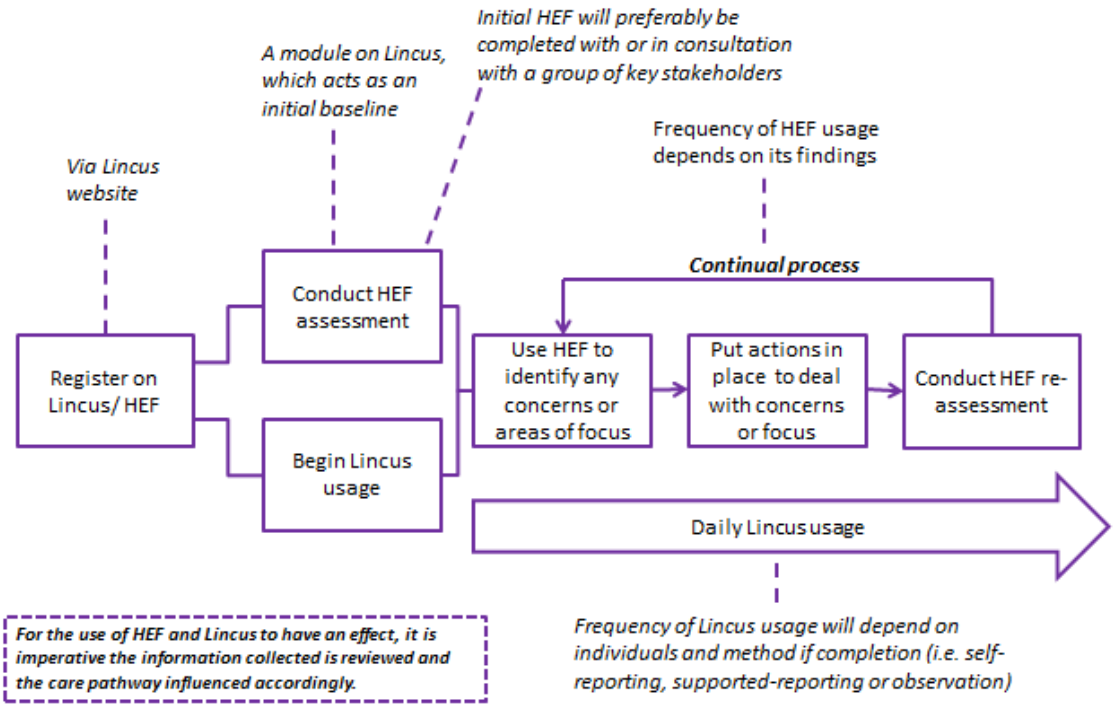


Figure 6.

On seeing both HEF and Lincus, Hft felt there were strong synergies between the two and the approaches were complementary: one (Lincus) gives an ongoing picture of health and wellbeing over a period of time; the other (HEF) gives a periodic snapshot of health inequalities, whilst establishing priority areas for attention. The integration of HEF into the Lincus platform allowed greater collation, comparison and analysis of the data collected, whilst also supporting aspirations of integration between health and social care. It also ensured greater data security and protects the integrity of the HEF: an Excel spreadsheet is also more easily adapted or amended, taking it away from its original purpose.

The following flow diagram shows how we have used HEF and Lincus within the project:



The integration of HEF and Lincus was completed early on in the project and well ahead of schedule. This allowed us to work with the two test sites to introduce the system in their own time, following training in both – by the Hft PT team and HEF author. We specified that Lincus and HEF should be used on a tablet device to enable recording to take place 'in the moment', maximising the benefits of mobile technology. In Bradford, 28 people with learning disabilities supported by Hft were part of the project and had an initial HEF assessment completed (in February 2016). This exceeds the minimum number we originally specified, providing additional data for the evaluation. In Gloucestershire, 25 individuals had an initial HEF assessment (completed in April and May).

Initially, we requested that Lincus be used on a daily basis – however, due to workloads and individuals' preferences and feedback, we agreed the operations teams can decide how often to use Lincus on a case by case basis with a minimum usage requirement of once a week to ensure enough data was collected.

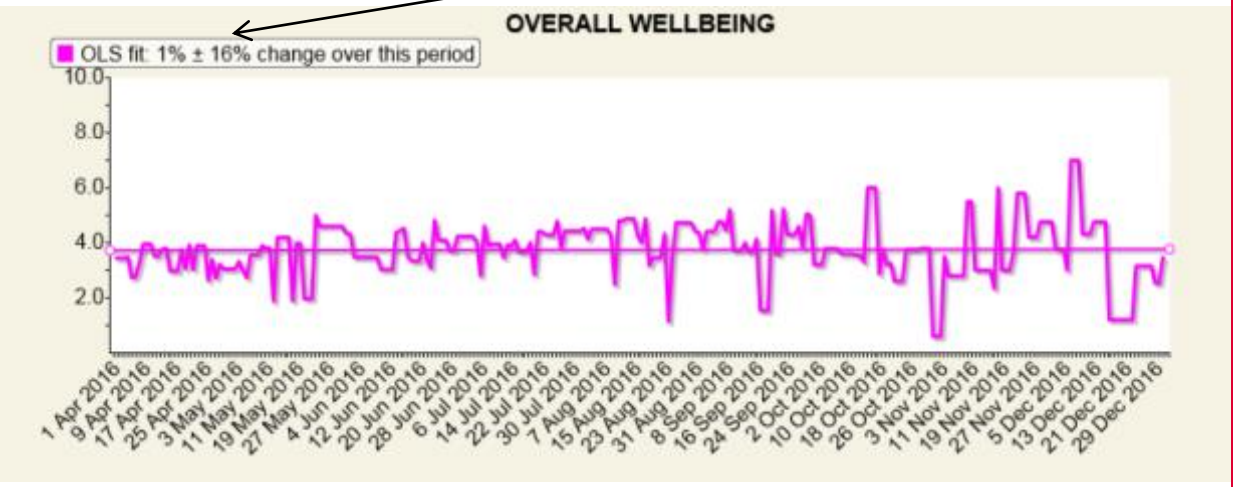
Another adjustment we made during the initial stages of the project was the creation of the Lincus observation module. Initially Lincus was used in two ways: simple self-reporting by individuals with learning disabilities (who are able) and supported self-reporting with help of (in this project) a support worker. However a third scenario became apparent, where an individual either chose neither of the other options but staff felt it was important to record their feelings, behaviour, an event or intervention or they were unable to make the decision for themselves. Therefore the observation module was developed in order to distinguish between the three approaches to recording.

Results

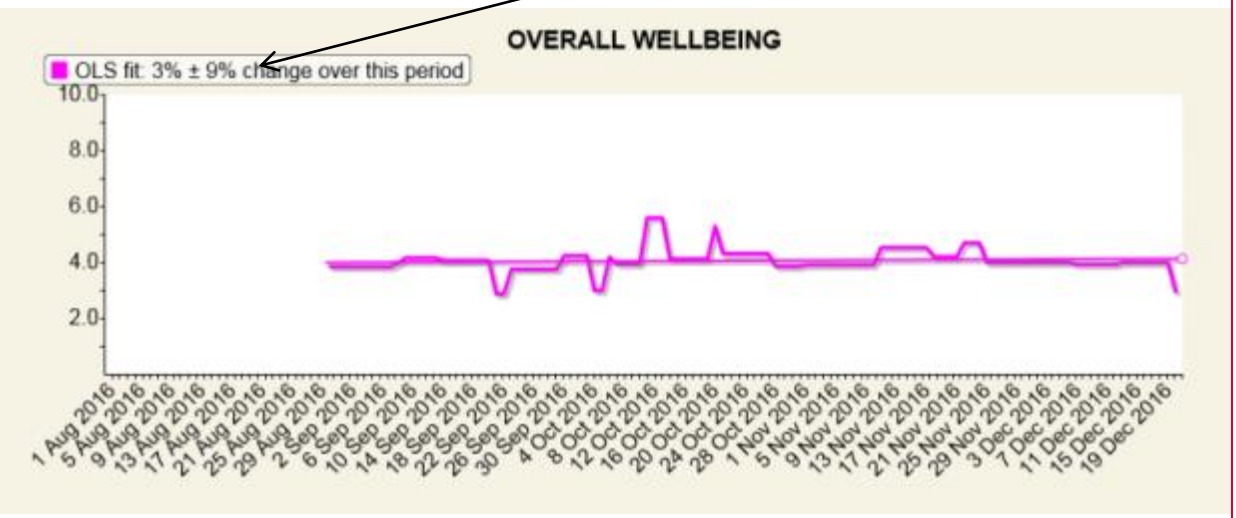
The primary data which was analysed was the HEF scores – i.e. people's exposure to the known determinants of health inequalities. This was supported by the Lincus wellbeing data. In effect, HEF records the baseline or starting point and periodic milestones and Lincus tells the story of the journey in between. Lincus is both the medium for recording the data collected and also for its collation and basic analysis. Lincus is a responsive system: the more data recorded, the more insights and analysis that can be drawn from it.

Overall, people's wellbeing improved during the project:

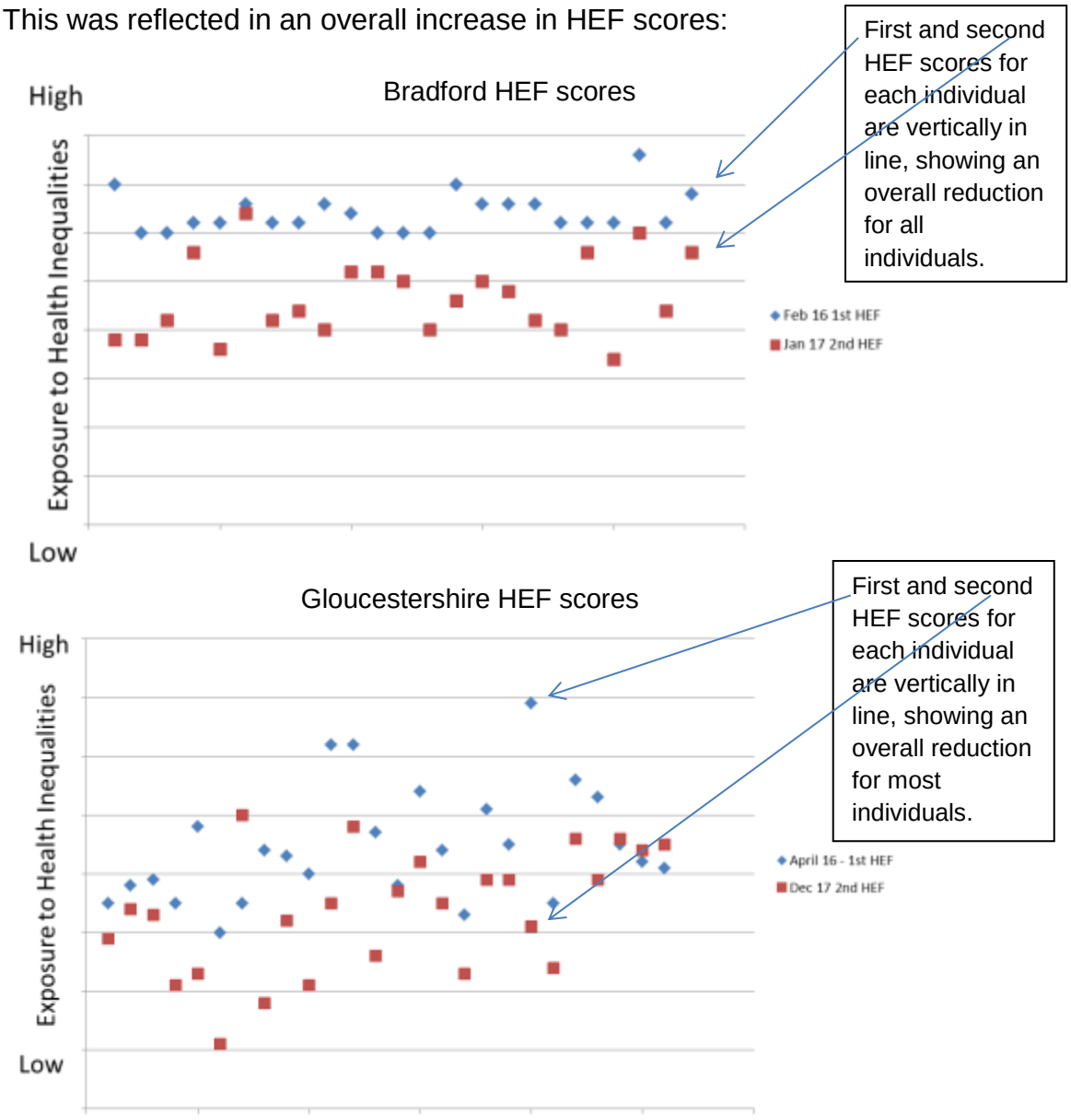
Bradford: ***demonstrating a 16% increase in wellbeing scores:***



Gloucestershire: ***demonstrating a 9% increase in wellbeing scores:***



This was reflected in an overall increase in HEF scores:



A key theme has emerged from each of the pilot sites, which is in part a reflection on the circumstances which were present but also serves to underline the importance of the information gathered and tools with which to analyse it.

Gloucestershire – The significance of appropriate and stable housing: In Gloucestershire a significant house-move project was scheduled for during the project, which was one of the reasons that the site was selected in the first place. For many people supported by Hft this was a move from a site that has been their home for many years but was no longer fit for purpose. Most people moved into their new homes, which had been either purpose-built or specially renovated to suit their needs and, for the first time for many, they had a choice about where they lived or who else (if anyone) they lived with. A small number have moved into temporary accommodation and several of these individuals have experienced worsening health inequalities, particularly around the areas of housing and isolation.

It is also worth noting here that some other individuals' HEF scores also worsened in areas such as diet, risky behaviours (for example alcohol consumption) and (lack of) exercise. This is also likely to be a reflection on the change to more suitable housing in a more community-based setting (although scores improved in areas socialisation and housing, which also support this). The original premises were in a small village with very poor transport connections and few local facilities. By moving to more suitable and better connected housing, people now have increased choice – to both make 'wise' and 'unwise' decisions, as well as the opportunity to take risks as many of their mainstream peers do.

> Lincus makes you ask the questions that you can sometimes overlook because you think it's an obvious question.
>
> Personalised Technology Coordinator, Hft

Bradford – The importance of enhanced communication: In Bradford, the individuals who attend the day service have multiple and complex needs and most are unable to communicate their wishes and needs verbally. The initial HEF assessments in February 2016 showed that staff struggled to make sense of non-verbal signs of pain or worsening health in people they were supporting. Therefore coffee mornings were held for families and carers to support them to complete a DisDAT (Disability Distress Assessment Tool) to support staff in recognising and responding to signs of pain and distress. This change in practice was subsequently reflected in reduced HEF scores. At the final reassessment in January 2017, almost all scores in communication (and behaviour) had significantly reduced.

Impact on original intended outcomes

These results also reflect the impact on our original intended outcomes and we achieved all of the outcomes that we set out to:

- Involve individuals in their own self-management, care and welfare: *achieved through regular use of Lincus, both the observation and regular versions.*

- Use the tool developed to reduce the impact of heatlh inequalities, improve health and wellbeing outcomes and improve support, as well as providing direct savings to health and social care providers: *overall we reduced the impact of health inequalities. Where HEF scores initially increased, it was largely a result of increased information (i.e. we knew more about people's health needs and inequalities) or increased choice for individuals. We did not achieve direct savings to health and social care providers. As the project progressed, it became clear that any savings would not be realised quickly (i.e. within the scope of the project timings); may be realised at a much later date, as initially costs may increase along with the knowledge we have about people's health; and savings made in social care may be realised in healthcare and therefore difficult to quantify.*

- The needs of people with learning disabilities will be identified and better communicated to the relevant stakeholders: *we have been able to better identify the needs of the people we support and communiate this to the*

relevant stakeholders. This has been particularly well realised in Bradford, where we were able to share insights with family members, who were then in turn able to use that information in meetings with health professionals.

- Staff will have greater insights into the needs of the people they support: *staff members reported having greater insights into the needs of the people they support. This was reflected particularly well in Bradford, where HEF will now be used as part of our work in transition when individuals are joining the day service from school.*

Learnings

What is the role of day services in social care? One of the major learnings from the Bradford trial was the question that was raised around where does the day service begin and end. On paper it's 9am-5pm Monday-Friday: however, this is rarely the reality. The project gave us much greater knowledge about people's health and wellbeing; thus enabling us to identify where the gaps in support are. We have learnt a lot about the support we thought was in place outside of Hft – particularly in the Bradford day services – and where Hft should be expected to fill those gaps, even though we may not be responsible for that part of a person's support. This raises questions about where the day service's responsibilities begin and end and how they work in partnership with where the person lives – be it with family members or other support providers.

There isn't a 'one size fits all' solution. The input and feedback of those individuals actually using HEF and Lincus has been central to this project. What has become apparent during the project is that HEF has been very useful for those individuals who cannot communicate their health needs or distress levels, for example the group in the Bradford day service at Piccadilly, whereas Lincus was less useful for those individuals where the only option was to make observations. For those individuals who are more able, at a smaller day service in Bradford and those individuals in Gloucestershire, Lincus was very helpful in giving greater insights into people's day-to-day wellbeing.

> I'm feeling amazing.
>
> Person we support, Gloucestershire

There's more than one way to embed an innovation. Due to the issues experienced in Gloucestershire and the mitigation strategies we put in place, the result was actually an alternative way to embed the usage of HEF and Lincus – in a sense, 'top down' versus 'bottom up'. In Bradford, the PT team trained operations staff; the equipment was introduced and usage of HEF and Lincus was widespread and staff engaged people we support: 'top down'.

In Gloucestershire, operations staff were trained and usage was still low. After several other attempts, this was mitigated by deploying a specialist member of staff from the PT team (who had extensive operations experience) to engage with people we support, first and foremost, and also staff. The result of this was, over time, people we support began to ask staff to use Lincus following their work with the PT team: in effect, 'bottom up'.

Image 2: a person we support in Gloucestershire using Lincus with a member of the Personalised Technology team.

Technology has a potentially important role to play in terms of:

- Collecting evidence about the health and wellbeing of individuals.
- Enabling people with learning disabilities to participate and influence their care and the management and their own health and wellbeing.
- Enabling people with learning disabilities to increase their opportunities to communicate.
- Enabling staff and families to contribute to the HEF.

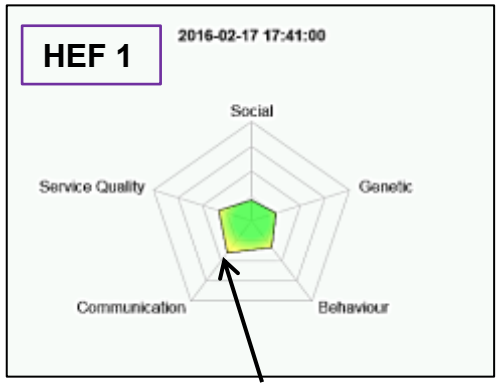
However, technology is only as good as the quality of information it collects and, fundamentally, how organisations like Hft use that information. The evidence gathered can change behaviours and support systems in a positive and person-centred way, but staff need to be motivated, seeing the value and positive results.

> People have short memories and when you look back you might only think of the week and see how someone's been. Whereas you can look with Lincus and you can see how someone's been over that month.
>
> Hub Leader, Hft Bradford

The following examples demonstrate some of the personal stories that have been collected through the project. Both individuals have had their exposure to health inequalities reduced substantially. One of them, after completing a house move that she was very negative about, has flourished in her new environment. She accesses local amenities, when previously she had to rely on staff, and has even made a new friend from a local social club. They now visit one another independently.

Story 1.

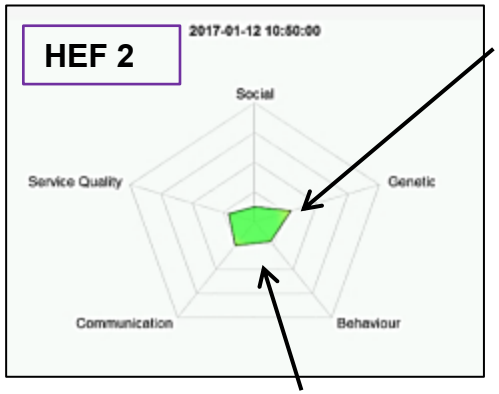
Shaun – Shaun attends the Piccadilly day service five days per week and also goes for respite stays at a local unit. He can become quite teary during this time, as he misses his friends and family. Shaun is a wheelchair user and needs hoisting by two members of staff at all times and sits on a sling whilst in his wheelchair at all times. He is a very sociable person who likes to be with people he knows well and has an infectious laugh and a lovely smile.



HEF scores in February showed some inequalities in communication and service quality.

Following the first HEF assessment, actions were put into place:

- Support plan changed to Health Plan and additions made to topics including equipment
- Health being discussed at reviews indicated some issues
- Signposted and referrals made to specialist OT
  - Health screening referrals made to health
  - Weight being monitored



Genetic scores increased, due to our increased knowledge of Shaun's health and wellbeing.

By December, these inequalities were reduced.

Shaun has started with a cough and has been sneezing a lot today.

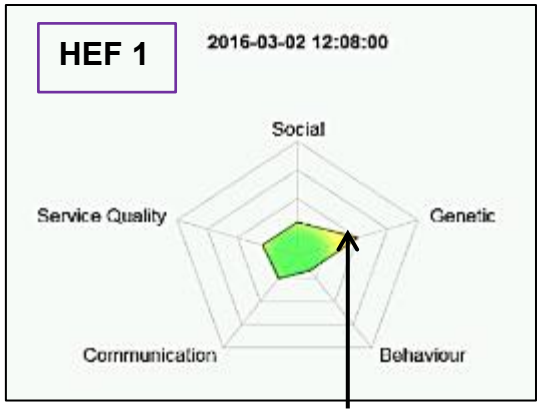
Overall wellbeing can be tracked against certain events or occurrences, such as worsening health.

Staff could also closely monitor Shaun's overall wellbeing through the increased insight from Lincus, such as a drop in wellbeing when Sean was unwell.

April 2016 – December 2016

Story 2.

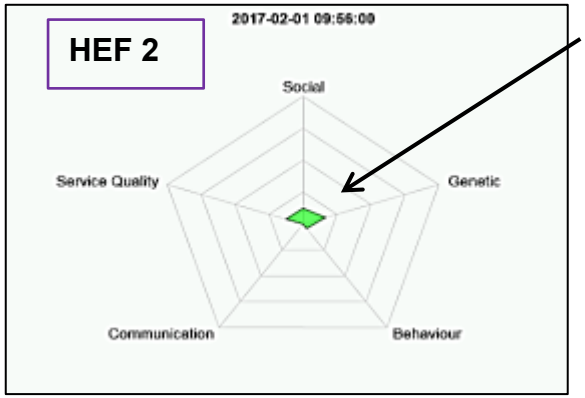
Caroline – Caroline currently lives at a large Hft campus-style site, Frocester Manor. She lives semi-independently in her own flat within a communal house, currently with three other people. Caroline enjoys this living arrangement, in particular having her own front door with a key and also a connecting door to the communal part of the Bungalow. She goes shopping every Tuesday, travelling to Stonehouse. Caroline also likes to keep in touch with her family and friends by letter, phone and e-mail. She was due to move to a smaller, self-contained flat in Stonehouse during the course of the project, which was a much more suitable property for her needs. Initially Caroline did not want to move house.



HEF scores in February showed some inequalities in genetic (related to no Health Action Plan), communication and service quality.

Following the first HEF assessment, actions were put into place:

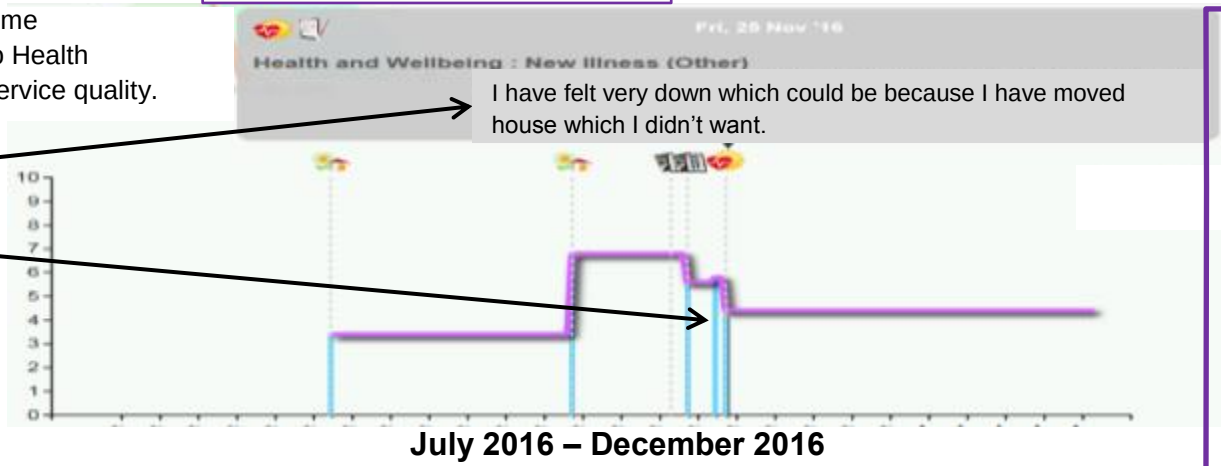
- Caroline's sister was heavily involved in supporting her to move house.
- A Health Action Plan was completed.
- Mental Health training was undertaken by the staff team.
- Additional support was given around her anxieties about moving house.



By December, these inequalities were considerably reduced.

Overall wellbeing can be tracked against certain events or occurrences, such as moving house.

Staff could also closely monitor the impact of the move on Caroline's wellbeing and put in place mitigation strategies.



July 2016 – December 2016

After moving to more suitable housing, Caroline has been able access local amenities such as shops, cafes and social clubs and has even started to make new friends.

Part 3: Cost impact

Key cost impact

The key cost measures as part of the project are the costs (or eventual savings) to health and social care. This has changed and become more complex as the project has progressed and as the lines between health and social care become increasingly blurred and where the respective responsibilities and budgets lie. This is highlighted in the work in Bradford through the provision of regular dental or hearing checks that staff had initially assumed were being accessed by family members or residential support providers. Not only might this save the NHS money through the reduced demand for treatment, especially emergency dentistry, but there are also reduced costs in areas such as challenging behaviour which may have been caused by unidentified dental pain or discomfort which are very difficult to quantify.

Health and social care budgets are currently separate, which further complicates the cost measures and analysis. For example, as Hft becomes more aware of the health and wellbeing of the people we support, the cost to the health service may actually increase initially due to additional diagnosis or monitoring. In the longer term, these interventions should represent savings to the health and social care service but these will take some time to be realised.

> It means there's no division between health and social: you can't have a social life if you're not in your optimum health. If someone is laughing and joking when we played bingo last week, then that means for me that they're not in pain, they're not suffering. It tells me a lot, doesn't it – just by watching somebody.
>
> Learning Disability Nurse, Bradford

To give an idea of the potential cost savings to the NHS: an intermediate dental procedure for an adult costs the NHS around £154. There are approximately 930,400 adults with learning disabilities in England. By preventing just 10% of these individuals (93,040) from having a dental procedure would save around £14million*.

Other interventions identified through this project, such as better distress or pain management or regular hearing checks, could produce similar savings if the process was replicated elsewhere**.

The cost of implementation has been and will continue to be modest. Now the development work has been done (integrating HEF and Lincus), the ongoing costs of implementation relate to hardware and staff time. To enable the training of staff, we have provided funds to back-fill support staff time and the Personalised Technology (PT) team members have delivered the training as part of their day to day workload. To truly embed this across Hft would require considerable efforts in training and coaching of staff, as well as the necessary licencing and hardware with which to deliver it. However, we still believe these costs will continue to be modest.

The key audience that Hft needs to influence in order to sustain the project and the interventions is commissioners: both health and social care commissioners, as well

as building the case for integrated health and social care budgets since this is where any savings and improvements to services will be best realised. Hft is attempting to take a holistic approach to the health and wellbeing of the people we support. To this end, social care has not been as helpful as it might have been in identifying the determinants of ill health and how it can best intervene to mitigate this.

Current commissioning structures do not lend themselves to projects and systems such as this one, since social care (and health care) is commissioned on the basis of what is 'wrong' with someone – disability, rather than ability. If providers like Hft make people more independent, then they receive less money in fees – thus creating a 'perverse incentive' to do so, despite it being the right thing to do. Regulators, such as the Care Quality Commission (CQC), are also a key influencer in supporting such a change to commissioning. In addition, most commissioners expect to see technology being used in services for people with learning disabilities – however, very few appear willing to budget for it.

Image 3: the Hub Leader in Bradford supporting a person to use Lincus.

*The National tariff payment system 2015/16 states that an intermediate dental procedure costs £154: https://www.gov.uk/government/consultations/national-tariff-payment-system-201516-a-consultation-notice. The Learning Disability Observatory estimates there are 900,900 adults with learning disabilities: http://www.improvinghealthandlives.org.uk/securefiles/170131_1512//People%20with%20learning%20disabilities%20in%20England%202013.pdf
By preventing just 10% of these individuals from having to have a dental procedure, the cost savings would be: 900,900/10 = 90,090. 90,090*154 = £13,873,860.

**Minor ear procedures cost around £115 and minor pain procedures £167. Applying these costs to 10% of the learning disability population could realise potential cost savings £10,360,350 and £15,045,030 respectively.

Part 4: Learning from your project

Project achievements

Overall the project achieved everything it set out to. There will be certain positive impacts that will not be realised during the life of the project, or even in the immediate aftermath, such as the full impact of identifying those at risk of health inequalities and the responses from relevant stakeholders including commissioners, primary and secondary care and families. However, we strongly believe that the project and its related interventions have provided insight and evidence of the benefits of focusing on the health and wellbeing of people with learning disabilities – both on an individual level and as a population. It's also highlighted the benefits of social care providers being guided to enhance people's wellbeing and the application of such interventions to prevent health inequalities. It has also prepared the ground for these impacts to be fully realised and capitalised upon once commissioning and regulatory structures allow.

The people involved have been integral to the project's success. In particular, three specific groups: the Personalised Technology (PT team); Hft's Health and Wellbeing group; and the Operations team in Bradford.

Image 4: a person we support in Bradford having their pulse taken.

The PT team were hugely important in setting up the project. They were responsible for training; identifying the most appropriate hardware; collating feedback and amends on the software; embedding the technology into everyday practice; and supporting staff to complete the assessments and surveys. Without their input, implementation of the necessary tools and devices would have been a great deal more challenging.

Hft's Health and Wellbeing group acted as the project's review group and, in fact, came up with the original concept for the project. Their great strength is that, due to its membership, the group has both internal and external credibility in the areas of health and social care.

The Operations team in Bradford have been consistently committed and enthusiastic about the project. They have integrated it into their day-to-day work seamlessly and have provided valuable insights, feedback and developments throughout. They see the bigger picture and the potential for innovations such as this, even the immediate impact has not been realised – a view which the culture of social care doesn't generally support.

Project challenges

The only major internal challenge that the project faced was with engagement and involvement in Gloucestershire. Initially, via their membership of the Health and

Wellbeing group, Gloucestershire volunteered to be one of the trial sites and displayed continued enthusiasm for what the project was trying the achieve.

However, despite the enthusiasm of the manager, staff engagement and activity was very low. This was largely due to due to external pressures on staff and recruitment issues which resulted in a reliance on temporary staff, as well as a cultural barrier related to living or working in an intentional community (where the project was initially based) which is one of learnt dependency and this project is challenging the very foundations of that culture. We were also working with a group of staff and supported individuals who were in the midst of a protracted move-on from the original Hft site, where many of them had lived or worked for more than 20 years. This was a move that was initially unwanted and deemed threatening by family members and other stakeholders – although it has now been almost universally welcomed.

The reason we persevered with working with this site was due to the anticipated benefits that moving from an intentional community, to supported living can bring, the support for this move from the local authority and the opportunity to capture the impact of such a move on people we support.

After several attempted resolutions to the issues from within the service, and following an unexpected two month absence of the manager, we took the decision to second a member of the PT team to undertake Lincus surveys on a weekly basis, supported by a member of the Hft specialist skills team who has an in depth knowledge of HEF.

This strategy proved successful in the main; although it became apparent that the entering of events and interventions into Lincus on only a weekly basis does not allow staff or users to fully appreciate the effects of this tool.

> Lincus and HEF will be one of a number of substantial changes.
>
> Operations and Project Manager, Hft Gloucestershire

This approach had an unexpected, but positive, outcome overall. Rather than the way the system was introduced in Bradford (i.e. a 'top down' approach), where staff were introduced to the system and then worked with people we support, in Gloucestershire we introduced the system to people we support via a specialist member of staff. People we support appeared to see the benefits of using Lincus and HEF and, over time, began asking staff members to use it with them. This, coupled with interest shown by a local CQC inspector in the benefits of daily recording, has led to staff becoming more engaged with Lincus – in effect, creating 'bottom up' approach to embedding.

There is an external and fundamental challenge which remains and could impact the long-term success of this project: that is the commissioning of services based on numbers of hours and hourly rates, rather than outcomes. This is largely present in social care and represents a perverse incentive to service providers to improve outcomes that may result in reduced support hours (and therefore a reduction in fees). It is a structure which is mirrored in the NHS in the form of the tariff system

and payment based on levels of activity. This remains an ongoing obstacle but Hft is working towards building evidence to support commissioning based on outcomes (which this project will make a major contribution towards).

Introducing and sustaining innovations in the NHS

These challenges serve to highlight some of the issues around introducing and sustaining innovations within the NHS. The fact that this project contributes to the whole self-care agenda has been part of its success, however the long-term sustainability of it remains uncertain without a change to commissioning structures.

Advice to others

For others attempting a similar project, our main advice would be to develop a true working partnership in all aspects of the project. In particular, with any external partners, to ensure solid due diligence and conflict resolution strategies and ensuring long-standing working relationships are developed. This is particularly relevant with commercial partners, where they are looking to sustain their business or make a profit. Strong partnerships are also paramount within one's own organisation, including support from key members of staff (such as senior management teams and specialist teams, in this case the Hft PT team) and ensuring they understand what it is you are trying to achieve. Another key element to long-term success in a project such as this is ensuring that its aims and objectives resonate with those of the organisation. In addition, when considering technology specifically, it is important to understand your organisation's approach to technology and where any potential barriers may be.

Part 5: Sustainability and spread

Sustaining the intervention

The intervention of using HEF and Lincus to provide a baseline and record outcomes for individuals is being supported by Hft in areas outside the Innovating for Improvement sites and is planned for beyond the funding period. We have gained support for the innovation throughout the life of the project, through regular reporting and updates, and have been able to capitalise on supporting Hft to achieve its wider objectives (i.e. building evidence for commissioning based on outcomes).

Biggest risks and challenges

The biggest challenge we face in embedding our innovation into routine practice is systemic resistance to it becoming business as usual. This encompasses both staff resistance to new ways of doing things and indirect resistance from regulators and commissioners as they do no request or require this type of information, despite the valuable insights it provides. Consequently, providers such as Hft cannot build this type of offering into the fees for our services even though it will likely lead to an overall saving and increased quality of life for people we support. It is worth noting that one of the motivators for engaging staff with Lincus and HEF in Gloucestershire was a comment from a local CQC inspector about the benefits of daily recording.

The biggest risk we face in embedding our innovation is that either of our external partners may become commercially unsustainably: the creators of Lincus and HEF. If Hft does not find a solution to the system resistance mentioned, then both these solutions will become commercially challenging.

We have begun to engage with key stakeholders, such as the Association of Directors of Adult Social Services (ADASS) to overcome these challenges. ADASS have shown some initial interest in using HEF and Lincus together and we are continuing our dialogue with them, as well as other key stakeholders. We also plan to use the evidence generated from this project to support Hft's work with the development of outcome-based commissioning, as well as continuing to raise the profile of how technology can support people in a more cost-effective way which also improves outcomes and quality of life.

Spreading the innovation

We do have plans to spread our innovation beyond the Innovating for Improvement sites and some of these are already under way. We successfully trialled the use of video-consultation with people we support, linking them initially to family members but with an aspiration to link to healthcare professionals in the future. This project - 'Better Outcomes for People with Learning Disabilities – Transforming Care' (BOLD-TC) – also used HEF as baseline, as well as regular Lincus usage to provide evidence of the outcomes. Whilst, internally, this project proved the concept that the people we support may find video contact beneficial (which the majority in the trial did), current commissioning structures were not supportive of the mainstream roll-out of the equipment and, unfortunately, the provider of the equipment (v-connect) ceased trading. We continue to explore opportunities in this area.

Hft also has another internal project called Fusion+, which is taking Hft's Fusion model of support* and supporting it to create an even better service for the people we support, based on outcomes. This project also uses HEF as a baseline, as well as Lincus to provide the evidence of improved outcomes. This project is due to finish at the end of March 2017, when we will be reviewing the evidence and impact.

As Hft is a charity, with limited funds, funding is of course a key priority for the sustainability of the project. To this end, we have begun exploring additional funding opportunities (both within the Health Foundation and outside, such as the Small Business Research Initiative) as we look to widen participation throughout Hft. Hft is looking to see how we can use Lincus and HEF more widely and embed these systems across Hft, helping us develop a holistic approach to the health and wellbeing of the people we support.

External interest and recognition

The project has generated some considerable interest in Hft, our work with technology and also looking to reduce health inequalities for people with learning disabilities. We have been invited to contribute to academic research and deliver presentations at national events, based on our involvement with this project. Some key examples include:

1. Being invited to delivering a presentation at Digital Healthcare Revolution: Harnessing NHS Technology on 25 February 2016.

2. Invitation to present the project to the Gloucestershire Health Action Group on 12 May 2016, and again on 29 November 2016.

3. Invitation to present the project at the Gloucestershire Big Health Check Day on 25 May 2016.

   Overview of the event on YouTube:
   https://www.youtube.com/watch?v=4hvRgfHi5EA

4. Invitation to contribute to a workshop hosted by NHS England and UCL on how to improve outcomes for people with learning disabilities, which took place on 26 January 2017.

   NHS England has commissioned The UCL Institute of Health Equity to provide up to date information about inequalities in health and wellbeing as they relate to people with learning disabilities, and critically, to identify effective interventions in the areas of education, housing, social care and employment. The report will detail findings, make recommendations, and focus on how we can improve opportunities for people with learning disabilities of all ages.

   The researchers have shown interest in our project and how it can inform their research.

5. Invitation to speak about the project at 'Learning Disabilities: Improving Care and Outcomes' forum, held on Wednesday 8 February 2017.

Upcoming milestones and activities

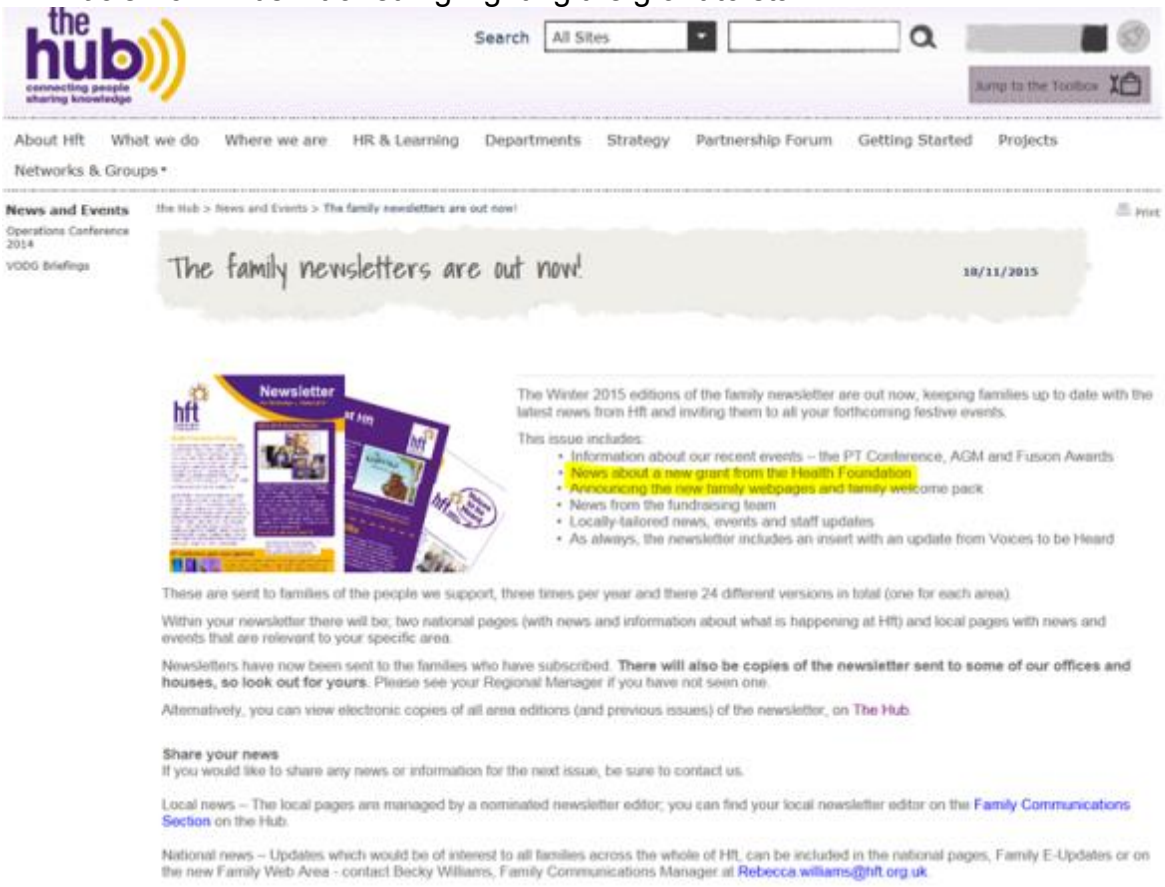
Beyond the Health Foundation funding, we intend to continue use of Lincus and the HEF within Hft, for those groups of people it has been effective for, and using these findings to contribute to our growing body of evidence to support outcome-based commissioning. The wider Hft project in this area, Fusion+, comes to an end in March 2017 which represents a key milestone within Hft.

We are also exploring further development and funding, in partnership with Rescon, to further develop the system to incorporate video-consultation and generate some funding to further test this concept. We plan to apply for the Health Foundation programmes Spreading Improvement and Scaling Up Improvement, as well as additional funding programmes such as the National Institute for Health Research (NIHR).

*Hft's Fusion model of support: http://www.hft.org.uk/Supporting-people/fusion-model-of-support/

Appendix 1: Resources and appendices

1. Article from Hft's intranet highlighting the grant to staff:



2. Example of Hft's social media activity around the project:

Hft Personalised Technology
January 13 at 11:15am

Some of the PT team are filming in our Gloucestershire service today, for the health foundation project. We are talking about the benefits of using a system like Lincus for the people we support.

3. Coverage of the grant in Hft's family newsletters, which are sent to family members of the people we support:

Newsletter

For Hft families ▪ Winter 2015

hft
Creative ideas
Fulfilling lives

Health Foundation Funding

Hft has been selected by the Health Foundation, an independent health care charity, to be part of its £1.5 million innovation programme, Innovating for Improvement. The project will take Lincus – an existing application designed to track health and wellbeing and allow people to better communicate how they are feeling – and integrate it with the Health Equalities Framework (HEF) – an outcomes-based framework which identifies health inequalities. The project will be undertaken in Hft services in Bradford and Gloucestershire.

Sarah Weston, Innovation Manager for Hft said: "We are really delighted to be working with the Health Foundation on this exciting and innovative project – particularly as Hft is the only third sector organisation to be awarded a grant in this round. By being better able to monitor health and wellbeing, we will be able to offer better and more targeted support – ultimately improving outcomes for the people we support. In addition, these insights can be shared with a variety of stakeholders, allowing them to play their part in improving the health and wellbeing of people with learning disabilities."

Hft's 2015 Annual Review

This year's annual review is now published on the Hft website! Our review features highlights from Hft throughout 2014 and 2015 – including fundraising activities, royal events, our Person-Centred Active Support training and the achievements of our Voices To Be Heard group. It also outlines Hft's current challenges and goals for 2016. The Annual Review is an environmentally friendly, interactive e-brochure, complete with clickable icons, videos and links which you can download at:

www.hft.org.uk/annualreview2015

Pictured below left: (L-R) Hft's Strategic Director of Innovation, Steve Barnard; Hft

4. Media coverage in Pos'ability magazine:

HFT WINS INNOVATION AWARD TO IMPROVE WELLBEING OF PEOPLE WITH LEARNING DISABILITIES

A team from **Hft** – a national charity supporting people with learning disabilities – has been selected by the Health Foundation, an independent health care charity, to be part of its £1.5 million innovation programme, Innovating for Improvement.

The second round of the Innovating for Improvement programme is supporting twenty-one health care projects in the UK with the aim of improving health care delivery and/or the way people manage their own health care by testing and developing innovative ideas and approaches and putting them into practice.

The initiative from Hft will take **Lincus** – an existing application that tracks health and wellbeing and allow people to better communicate how they are feeling – and integrate it with the Health Equalities Framework (HEF) – an outcomes-based framework which identifies the impact of services in reducing exposure to known determinants of health inequalities. This development will allow Hft to better monitor the health and wellbeing of people with learning disabilities supported by the charity, with the ultimate aim of improving long term health and wellbeing outcomes for this group.

Integrating Lincus and the HEF will allow for much easier collation and analysis of health and wellbeing information; and improve the quality and timeliness of interventions, solutions and actions.

The project will be undertaken in Hft services in Bradford and Gloucestershire and builds on the findings from *Death by Indifference* and the *Confidential Inquiry into Premature Deaths of People with Learning Disabilities*.

Over the course of the programme the team will develop its innovative idea and approach, put it into practice and gather evidence about how the innovation improves the quality of health care and wellbeing insights.

The team will be led by Hft's Personalised Technology team, working closely with the creators of Lincus, technology SME Rescon, and the creators of the HEF.

Sarah Weston, Innovation Manager for Hft said: "We are really delighted to be working with the Health Foundation on this exciting and innovative project – particularly as Hft is the only third sector organisation to be awarded a grant in this round. By being better able to monitor the health and wellbeing of the people Hft supports, we will be able to offer better and more targeted support – ultimately improving outcomes for the people we support. In addition, these insights can be shared with a variety of stakeholders, allowing them to play their part in improving the health and wellbeing of people with learning disabilities."

Gill Clayton, Programme Manager from the Health Foundation said, "We are very excited to be working with such a high-calibre of teams, who all have great innovative ideas. As an organisation we are keen to support innovation at the frontline, therefore I am pleased that we will be able to support these ambitious teams to develop and test their ideas over the next year.

"Our aim is to promote the effectiveness and real impact of the teams' innovations and show how they have succeeded in improving the quality of health care, with the intention of these being widely adopted across the UK health service."

The programme will run for fifteen months and each project will receive up to £75,000 of funding to support the implementation and evaluation of the project

5. Presentations from speaker opportunities:

6. Link to one of five short films about the project: https://drive.google.com/file/d/0B_LhA88lWIz4Z2p4dzFURWc0UVk/view?usp=sharing

7. Project evaluation report prepared by the Bayswater Institute.

Bayswater Institute
Evaluation of Lincus f