

Report of: Directors of Adults & Health and Resources & Housing

Report to: Executive Board

Date: 20th September 2017

Subject: Delivery of the Leeds Person Held Record (PHR) programme

Are specific electoral Wards affected? If relevant, name(s) of Ward(s):	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Are there implications for equality and diversity and cohesion and integration?	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No
Is the decision eligible for Call-In?	<input checked="" type="checkbox"/> Yes	<input type="checkbox"/> No
Does the report contain confidential or exempt information? If relevant, Access to Information Procedure Rule number: Appendix number:	<input type="checkbox"/> Yes	<input checked="" type="checkbox"/> No

Summary of Main Issues

1. Leeds has a growing reputation for developing digital solutions that support the health and well-being of its citizens. This report details a development that will enable Leeds citizens to have access to a more holistic view of their own health and local authority services information. This will enable them to get more actively involved in looking after their own integrated health and care needs. Although take up will be voluntary, this initiative will be innovative and empowering for individuals. The Leeds Informatics Board (LIB) have given their support to proceed with a Leeds 'Person Held Record' (PHR) programme with Leeds City Council taking the lead on behalf of the wider city. Following the review of a comprehensive business case, Health partners within the city have prioritised the use of the capital allocation included within the Better Care Fund in Leeds and have given approval to allocate capital funding totalling £1,800K across three years with the release of £590K in year one of the programme. Annual gateway reviews will ensure the programme delivers its agreed scope and objectives and future years funding will only be released following successful gateway reviews.

Recommendations

1. Request that Executive Board give approval to initially incur expenditure of £590K (year one) of a total of £1,800K over three years to develop and rollout the 'Personal Held Record' in Leeds for the reasons outlined in this report. Subsequent releases of funding will be subject to successful progress and gateway reviews.

1 Purpose of this Report

- 1.1 The purpose of this report is to seek approval to initially incur expenditure of £590K (year one) of a total of £1,800K over three years to develop and rollout the 'Personal Held Record' in Leeds for the reasons outlined in this report. Subsequent releases of funding will be subject to successful progress and gateway reviews.
- 1.2 This will primarily involve the development, hosting and rollout of a PHR platform and the engagement of specialist internal and external resources and suppliers to commission, develop and implement this initiative. LCC will lead this on behalf of the wider city.

2 Background Information

- 2.1 Leeds has established itself as a city at the forefront of 21st century health and care delivery. In size and scale, it is a microcosm of the health and care system in England. Through a combination of thought leadership, organisational change and leading technologies, the city presents itself as an exemplar for a range of initiatives under the banner of 'Place as Platform' - which includes integrated care in the form of the Leeds Care Record (LCR).
- 2.2 Ongoing pressures across the health, care and local government services in Leeds have resulted in leaders across the city exploring new and better ways of working.
- 2.3 In line with emerging good practice in other places, city informatics leaders have agreed that the time is now right to progress a 'Person Held Record' (PHR) initiative so that people can take greater control over their own health and wellbeing in order to help prevent health conditions or take action sooner to treat emerging conditions. This approach is set to deliver significant benefits. A key theme within the Leeds Health and Care Plan is to enable citizens to self-care and self-manage in relation to their health and social care needs. Holding and maintaining control over their own personal data together with that held by Health and Social Care Professionals is critical to supporting this agenda. A simplified schematic of the PHR is shown in Appendix 1.
- 2.4 Engagement and insight undertaken with Leeds citizens as part of the 'Joined up Leeds' initiative [Joined up Leeds 2 \(Citizens\)](#), indicates positive support for a more integrated and consistent view of their own information, as well as a desire to contribute relevant information to help inform their individual health and care needs.
- 2.5 The Leeds PHR programme will place citizens at the centre of and more in control of their own health and care needs. People will be free to choose how much or how little they want to make use of the functionality of Person Held records.
- 2.6 LCC is well placed to take the lead on this programme on behalf of the city as part of a collaborative and partnership orientated approach with both public and private sector parties.

3 Main Issues

- 3.1 Whilst this proposed approach will build on internationally leading open and reusable technology developed over a number of years by the Ripple Foundation C.I.C, access to a truly integrated/joined up record for citizens has not been undertaken before. However, as a leader in informatics across the UK, Leeds as a city has undertaken projects similar to this with the highly successful Leeds Care Record (LCR), which provides health and social care professionals with a joined up and consistent view of the patients/citizens in their direct care. With proven experience and support from city leaders, the PHR represents the next logical step in the pursuit of truly integrated and transformational care.

- 3.2 The Leeds PHR will be built upon on the established open platform developed by Ripple and will provide the opportunity to be readily shared with others so creating communities / capabilities (clinical, business & technical) around it. The ambition of the approach proposed will support the aims of the Leeds Health and Care Plan and could also support the wider West Yorkshire and Harrogate Sustainable Transformation Plan (STP) ambitions and in time become a national open platform exemplar for widespread adoption. Should multiple places implement the same solution, contributions and enhancements to the same open platform and product could be readily shared and be reusable by others, saving time, effort and making the approach sustainable. This aligns well with the Simplify, Standardise and Share principle promoted by the Council.
- 3.3 The benefits of the PHR are anticipated to be significant across the Leeds health & care system. These benefits will predominantly be about releasing capacity in the Health system to help meet ever increasing demands rather than realising cash savings. Capacity will be released for example by overall reductions in visits to hospital emergency departments and GP surgeries as well as making less phone calls to GP's. Doctors will have immediate access to blood pressure readings and administration will be improved by change of address details being made at source by patients and a reduction in letters sent by post.
- 3.4 Health Commissioners will be encouraged to own and capture the benefits from the PHR to ensure that the productivity gains are taken account of in future CCG/LTHT contract rounds. The business case estimates that 1150 active users will see break even over 5 years on the £1,800K investment by reducing emergency department visits, GP visits and phone calls. 1% of the Leeds population – 7500 active users would see nearly £12M of benefits over 5 years, part of which will be used to fund the ongoing support of the PHR.
- 3.5 Access to personal information by citizens will bring new challenges and opportunities. The intention is to collaborate with both NHS Digital and the Cabinet Office's Government Digital Services (GDS) team to ensure that best practice is applied and Leeds can inform the wider thinking for other cities and towns across the UK. As part of this collaboration, the intention would be to pilot and utilise "gov.uk's" citizen verification technology – 'Verify' for citizen registration and authentication - [Gov.UK Verify](#).
- 3.6 The risk of cyber threat is increasingly an issue across all organisations as the risk of serious damage to critical computer systems and the information they host continues to rise. LCC in leading this programme, has significant obligations to comply with a range of security frameworks mandated across local government e.g. PSN (networks), PCI (credit card payments) and the new DPA (Data Protection Act). The criteria for compliance with these frameworks are becoming reassuringly more demanding and with work already underway within the Council to adhere to these protection and assurance measures, LCC is well placed to lead this work.
- 3.7 Identifying and active engagement with the citizens of Leeds is the key to the success of this programme. The right pilot group, motivated and actively engaged in supporting and using a PHR will be essential to informing early learning as well as preparing for future scaled up rollout across Leeds over time. This pilot group will be aligned to the Leeds Plan to ensure the programme delivers against the ambitions and intentions of the city. Although take up will be voluntary, this initiative will be innovative and empowering for individuals. This programme will be a key part of that plan. The development of the Leeds Care Record has demonstrated the importance of effective engagement, with the LCR having seen growth from 500 at the outset to 4,500 presently.
- 3.8 A commitment to consistent communications and engagement both with citizens and front line staff will be essential to success. This is recognised as a significant risk, and therefore communication and engagement is a key built in component of the programme. Without consistent communication of information regarding progress, benefits and risks/issues to all

the relevant stakeholders, the programme will potentially struggle to bring people along on this ground breaking endeavour. This kind of commitment has been proven to work with initiatives like the Leeds Care Record and Data Mill North.

- 3.9 This programme needs to be considered as a three year commitment to develop and embed the PHR successfully across the city and deliver against the anticipated objectives, outcomes and benefits. The internal/external recruitment and retaining of key personnel to support this programme will be important to ensure skills and knowledge are retained and to enable delivery at pace and scale.

4 Corporate Considerations

- 4.1 **Consultation and Engagement** - the Leeds PHR programme has been consulted on widely with both the citizens of Leeds as well as clinical, business and technical leaders across the city. The Deputy Leader of the Council and Executive Member for Strategy & Resources were briefed on the proposed programme in February 2017. The Executive Member for Health, Wellbeing and Adults has recently been briefed and also the Director of Adults & Health. The Deputy Chief Executive was briefed in December 2016 and the Director of Resources and Housing has also been briefed.

- 4.2 **Equality and Diversity / Cohesion and Integration** - the Leeds PHR platform will utilise web based technologies and will be highly accessible across a range of desktop, laptop and tablets as well as smart phone devices. Built on an open platform, the Leeds PHR will be customisable to meet accessibility standards.

The Health & Wellbeing strategy seeks to improve the health of the poorest the fastest. In parallel, the ongoing City Digital Inclusion initiative i.e. through the tablet lending scheme and training etc., is looking to help make sure that all citizens are digitally enabled and are hence able to take advantage of the PHR over time. This will enable them to take more care of themselves leaving our collective resources to focus on where they are needed most, and in particular within our most deprived communities.

Equality Screening and if required an Equality Impact Assessment will be undertaken as the programme develops.

- 4.3 **Council Policies and Best Council Plan** - The Leeds PHR programme is aligned with our Health & Wellbeing and Better Lives Best Council Plan priorities by supporting improved citizen centred care and self-care management.

Citizen access and contribution is recognised as a part of the requirement in the health and social care integration agenda that needs to be strengthened and this programme will seek to address this. The programme aligns with the [Leeds Local Digital Roadmap](#) and supports the Health and Wellbeing strategy for the city.

In a national context, the programme supports National Information Board (NIB) priorities around self-management and prevention - [Personalised health and care 2020](#).

4.4 Resources and Value for Money

4.4.1 Full Scheme Estimate

The anticipated capital cost for the Leeds PHR programme across the next three years totals £1,800K which has been approved by the Better Care Fund initiative as a fully funded government grant.

4.4.2 Capital Funding and Cash Flow

The Leeds Better Care Fund Partnership Board has approved the use of capital grant funding totalling £1,800K across three years with the release of £590K for year one of the programme. Gateway reviews will be put in place to ensure the programme delivers on its agreed scope and objectives as a key component of the Local Digital Roadmap/Leeds Plan. Future years funding will only be released following each successful annual gateway review.

4.4.3 Revenue

The precise revenue costs of supporting the PHR solution will be determined during its development. 1% of the Leeds population – 7500 active users would see nearly £12M of benefits over 5 years, part of which will be used to fund the ongoing support of the PHR.

4.5 Legal Implications, Access to Information and Call In

4.5.1 The hardware, software and services will be purchased through the Council's established preferred suppliers under existing contract arrangements wherever possible. The technologies involved are consistent with our agreed technical strategies and those of the wider city.

4.5.2 This decision is eligible for 'call in' and has been posted on the List of Forthcoming Decisions.

4.6 Risk Management

It is recognised that this is a pioneering programme in some respects but similarly were the successful Leeds Care Record and the Open Data Mill. Both were delivered successfully in Leeds through a collaborative approach and the adoption of robust and established programme/project methods that adopted strong risk and issue management. These same methods will be utilised during the delivery of this programme.

Growing pressures across the health, care and local government sector continue to increase which in turn demands a continuation of the shift away, at greater pace than that currently achievable, from the paternalistic delivery of citizen/patient services towards a more citizen/patient centred approach. The Leeds PHR programme will enable citizens of Leeds to get more actively involved in tending to their own integrated health and care needs as part of the prevention and self-management agenda. Without undertaking the Leeds PHR programme, the city runs the risk of at best not developing quickly enough to meet future demands or at worst perpetuating the status quo, which is clearly unsustainable in the medium term. Innovation around an open platform via the Leeds PHR programme will stimulate new behaviours and ways of working to allow front line staff to work smarter and will in time start to alleviate the pressures that are building up across the city and other places too.

5 Recommendations

5.1 Request that Executive Board give approval to initially incur expenditure of £590K (year one) of a total of £1,800K over three years to develop and rollout the 'Personal Held Record' in Leeds for the reasons outlined in this report. Subsequent releases of funding will be subject to successful progress and gateway reviews.

6 Background documents¹

6.1 None.

¹ The background documents listed in this section are available to download from the Council's website, unless they contain confidential or exempt information. The list of background documents does not include published works.

Appendix 1 – Person Held Record (PHR) – Simplified Concept

