SILVER: Smart Interventions for Local Vulnerable Residents

Connected Health Cities Care Pathway Project

Ruth McGovern[1], Deborah Smart[1], Kat Jackson[1], Stuart Wheater[2], Hayley Alderson[1], Alex Bowyer[1], Wendy Burke[3], Mary Connor[4], Lesley Davies[3], Tom Foley[1], Stephen Foreman[5], Val Hall[6], Ben Kaner[3], Helen Lancaster[4], Raghu Lingam[7], Lynn McMahon[4], Danny Meek[6], Kyle Montague[1], Alison Priestley[5], Jo-Anne Pringle[8] Judith Rankin[1], Helen Robinson[5], Gill Rowlands[1], Liam Spencer[1], Eileen Kaner[1]

[1]Newcastle University, [2]Arjuna Technologies Ltd, [3]North Tyneside Council, [4]Northumberland County Council, [5]Newcastle City Council, [6]Gateshead Council, [7]University of New South Wales, [8]South Tyneside Council

Abstract

Introduction: The Troubled Families Programme seeks to provide effective help through joined-up local services to the estimated 400,000 families in England and Wales who experience multiple and complex need. At the heart of the programme is information sharing between services. However evaluation of the programme found a failure to share information between services was a barrier to joined-up care. We aimed to explore public and professional views about data sharing and develop a platform to facilitate data linkage between primary health care and social care 'early help' practitioners.

Methods: Within phase 1 of the project, we conducted 35 semi-structured interviews with parents accessing early help services, 8 focus groups with practitioners supporting vulnerable families, and 12 semi-structured interviews with young people with varying experiences of accessing services. These findings were used to inform three co-production workshops with parents, children and practitioners in phase 2, wherein the interface design requirements were examined. In phase 3, the system was demonstrated within two workshops with local authorities to gather feedback.

Results: We found that parents did not have an understanding of who had access to their information presently and for what purposes. However, they were often willing for their information to be shared in order to improve the care they received. Practitioners identified the benefit of having access to relevant health data. Moreover, there is a willingness within primary care and social care to share information to improve care for vulnerable families, providing the legal basis of consent is met.

Achievements: The project has achieved the development of the SILVER system that uses the Medical Interoperability Gateway (MIG) to share GP data with social care staff. This system was well-received by social care practitioners supporting vulnerable families. The

project has fulfilled the governance and development requirements for information sharing to occur including producing information sharing agreements and achieving compliance with clinical risk management processes. Administrative delays have prevented data flow from occurring.

Introduction

It is estimated that around 400,000 families in England and Wales have multiple and complex need, including mental and physical health problems, involvement in criminal and anti-social behaviour, truancy, unemployment and domestic abuse [1]. The national framework for responding to the needs of vulnerable families, referred to as the 'Troubled Families Programme' seeks to identify and provide effective 'early help' through joined up local support. Early Help Services aim to offer timely early intervention which prevent, or reduce the severity of a family's problems through constructive challenge and building upon a family's strengths. Evaluation of the programme has repeatedly shown that failure to share information is a barrier to identifying and providing better services to vulnerable families [1]. The SILVER care pathway programme brings together leads from five regional local authorities, academics and researchers, IT specialists, local families and key workers, to explore how health and social care data can be shared, with the aim of improving care for vulnerable families meeting criteria for the Troubled Families Programme.

Methods

There were 3 linked phases to the project:

Phase 1

We conducted 35 in-depth semi-structured interviews with parents, in receipt of local authority 'early help' support, and close family members involved in providing direct care to the children. We examined their experience of help seeking and their views about the acceptability and helpfulness of their information being shared within the context of direct care. This was complimented by eight focus groups involving 47 practitioners from a range of organisations involved in supporting families (e.g. local authorities, education, health visitors, housing). The focus groups consisted of a scenario centred discussion based on Connected Health Cities (CHC) Amy's Page approach, followed by an in-depth group discussion examining the barriers and facilitators to information sharing between professional organisations. A further 12 field interviews were conducted with young people (aged 14-17) by a staff member on the SILVER project team who was also doing an MSc study. These interviews examined young people's views on the sharing of information relating to their health and wellbeing. The combined qualitative data gathered in phase 1 examined what information would be acceptable, feasible and useful to share.

Phase 2

Building upon the findings from phase 1, we conducted three co-design workshops involving a total of 10 parents, 9 children and 38 practitioners. The workshops used activities such as card-sorting, storyboarding and scenario discussion and provided data to inform the development of the SILVER user interface. In addition, surveys were completed with 34 early help practitioners to identify the information type of greatest priority to them.

Phase 3

We conducted two listening and development sessions with 11 Early Help practitioners from Gateshead Council and Newcastle Council. Within these sessions we demonstrated the SILVER data sharing system using test data; gathering views on user interface, functionality and usefulness.

All interviews were audio-recorded and transcribed verbatim and subject to thematic analysis.

Results

Phase 1 findings

The findings illustrated the range of agencies that parents and their children were involved with. Yet, despite probing, few parents gave a detailed account of how and when they had provided consent in the past for their family's information to be shared between these agencies. Their understanding was restricted to situations where information sharing would not require consent (such as in cases of child protection). They also did not fully understand how information was shared with parties involved in their care and the extent to which information might be shared. This led researchers to believe that parents could not have given explicit or informed consent for their information to be shared within their current care episode. Parents were however mostly willing to give consent for their information to be shared. They reported a wide range of mental and physical health difficulties. Parents perceived the sharing of information could be beneficial to their care, whilst also reducing the need to repeat their personal circumstantial information to multiple services and numerous practitioners involved in care delivery, as described by one Mum;

> *"I hate having to repeat myself… With us having mental health problems… I like just having the one worker. They all know that now because we've all sat and discussed it. Now she takes everything on and then she shares everything with everybody."*

Parents often reflected that information about their children was not shared in a timely way between agencies and this was a barrier to the care their children received.

Echoing the findings from the families, practitioners mapped a large number of different services which may be involved in a family's care. Information was regularly shared within existing multi-agency meetings with the exception of health information. Representatives from health were rarely in attendance at these meetings. Practitioners emphasised that information shared between services should be relevant, accessible and the amount of information they have access to should not overwhelm. Both adult and child health data were considered to be important information for the practitioners to be able to access. In addition, information on previous help seeking, current professional involvement and the type of interventions provided was identified as important in forming an understanding of the family's circumstances. Practitioners stressed the importance of information sharing at the earliest opportunity to ensure professionals can provide support at a preventative level rather than reactively.

Phase 2 findings

Co-production workshops

Key findings from phase 1 influenced the development of phase 2 of the project.

Key finding from phase 1: Processes and parameters of consent need to be clear.
Phase 2 development solution: The consent statement should make explicit to individuals what they are consenting to in terms of what information will be shared, who will be accessing the information and how it could be used. There should be a process of re-consent when accessing new information and when working with families over a long period. There should be a record of when an individual has refused consent. There was much discussion about whether the data view would be on an individual or family level. Overall, both parents and professionals thought data should be viewed on individuals with separate consents for each family member, particularly as sensitive information may not already be known by the whole family. However, as the early help services adopt a 'think family' approach, there was suggestion that family members' records should be linked to each other.

Key finding from phase 1: There are a large number of services involved in the care provided to vulnerable families.
Phase 2 development solution: The SILVER interface to include an event log, detailing the services involved and the named practitioner.

Key finding from phase 1: Information should be relevant, accessible and not overwhelm.
Phase 2 development solution: There was no consensus as to what was relevant, with both historic and current information being considered potentially relevant. This varied greatly depending on the family circumstances. A further action was taken to survey practitioners to determine the types and nature of information of greatest priority in their work, identifying mental health, substance use, missed and attended GP appointments, long-term conditions, referrals made to services, and prescribed medication as priority headings. This will then be used to filter the data view and enable the practitioner to manage the available data, promoting accessibility. A timeline presentation of data also to be incorporated to manage historical and current data.

System development and information governance

The development and preparation for implementation of SILVER has been dependent upon two core aspects; building the system and producing data sharing agreements and documents which demonstrate compliance with clinical risk management. The progress of both of these elements have been essential to enable SILVER to achieve its function, and have run alongside the research project.

Type of data to be shared

Results from phase 1 highlighted the significance of sharing adult and child mental health data. Thus, we explored the type of data that could be accessed and shared within the parameters of this project. Firstly, due to legal and practical considerations, and the sensitivity of sharing child data, it was decided that the SILVER proof of concept work should focus on parents' data only. From here consideration was given to accessing adult data which would be recorded by secondary mental health services. However, qualitative work in phase 1 found that most of the parents were not in contact with secondary mental health services. Rather they experienced common mental health problems managed by their GP.

Gaining access to data

The Improving Access to Psychological Therapies (IAPT) data held by NHS digital was explored as a potential source of common mental health data. Whilst the detail of data relating to patient referral and access of talking therapies was of relevance to the early help services, this data did not facilitate automated access. The time lag in available data was considered too significant to be of benefit to local authority practitioners in informing them about a parent's current health status.

Ultimately, it became apparent that immediate, automated data would be available via the Medical Interoperability Gateway (MIG). The MIG was chosen as the data supplier for the project. Access to GP data via the MIG enabled the project to widen the type of information shared to include all patient data, including mental health data.

To gain access to the relevant health data from the MIG, accreditation was required with the organisation behind the MIG – Healthcare Gateway. The accreditation process involved demonstrating that the SILVER system can correctly interact with the MIG in the form of protocol, message syntax and semantics.

System development – back end development

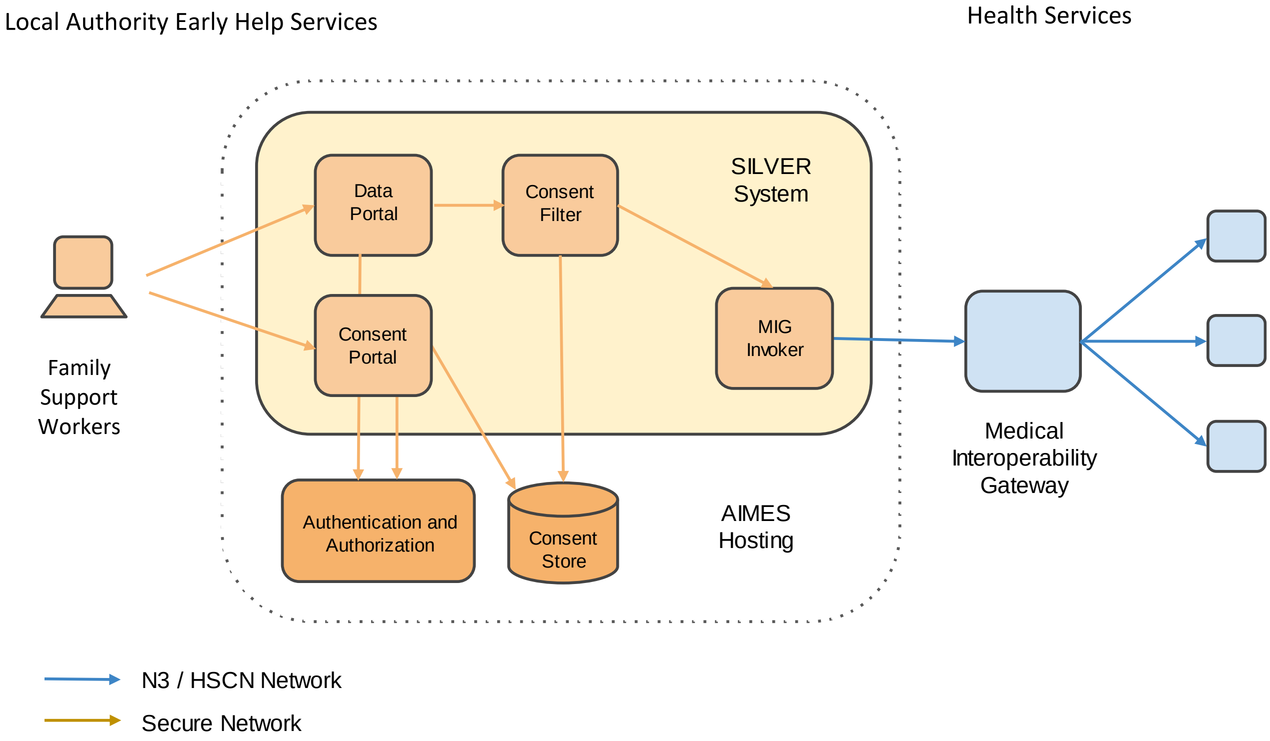

Diagram 1-SILVER system structure

Diagram 1 provides an overview of the structure of SILVER and the major functional components.

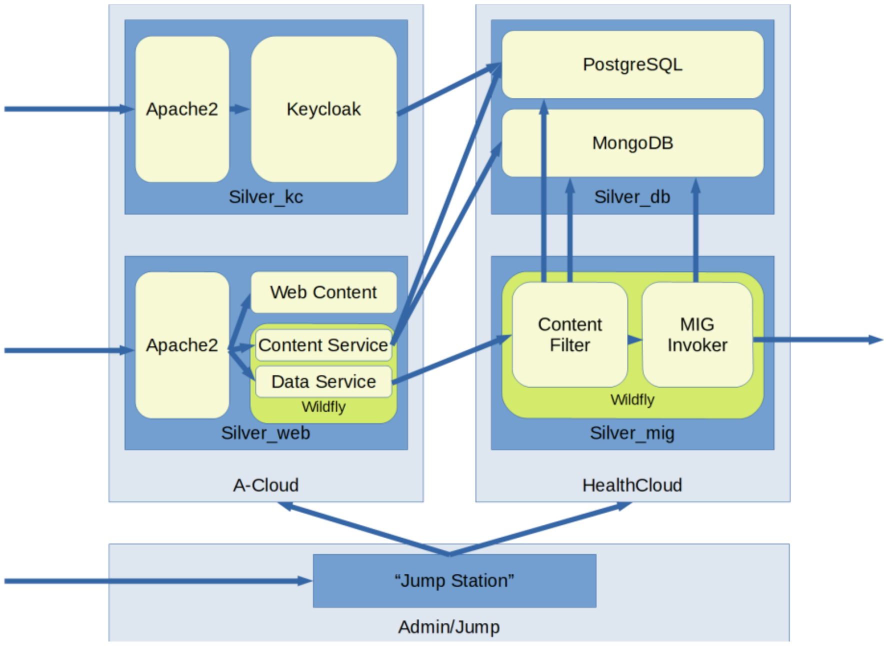

Diagram 2: SILVER System Deployment Structure

Diagram 2 details the configuration of the back end structure of SILVER system. It shows the 4 virtual machines VM): Silver_kc, Silver_db, Silver_web and Silver_mig, and the software deployed on those VMs.

System development – front end development

The SILVER front-end implementation is based on the open-source web application framework called Angular. The SILVER front-end needs to support registration of family groups and individual's consents, but its main purpose is to display medical information to family practitioners. The medical information needs to be presented in a manner which can be easily interpreted by family practitioners. To assist this presentation the context of the events are displayed in the form of a filterable time line and event log (Appendix 1). In addition to the medical events associated with a family members, it also provides access to the constellation of health care encountered by the family members.

Attempts to use GP READ codes to filter the data which practitioners considered priority areas were made. This proved to be a highly complex task and would not lend itself to replication due to the variance in how GP practices and individual GP's use them. Imposing a filter risked hiding inconsistently coded and relevant information from the practitioner's view, whilst presenting all unfiltered data may overwhelm and reduce accessibility of the data. A necessary balance was achieved whereby all data was presented to the practitioner, however a colour coding system was proposed to enable health information considered to be a priority by Early Help practitioners to be highlighted.

Information governance

In order to satisfy the information governance requirements, it was necessary for SILVER to produce two data sharing agreements; a detailed care record agreement outlining which data would be provided to be agreed by the GP practice and LA and a data sharing agreement outlining the purpose for which the LA would use the data. These information sharing agreements are underpinned by legal requirements and guidance that both local authorities and health services need to fulfil. SILVER includes the manufacture and implementation of software and as such, the project was also required to demonstrate compliance with Clinical Risk Management standards DCB0129 and DCB0160 prior to the authorisation of data sharing agreements.

Project achievements – SILVER system components

Consent portal

The development of a consent model and portal has been an integral part of SILVER and a notable achievement; it is required so patients know exactly what they are agreeing to and to ensure that it operates within the relevant legal framework. The consent platform is embedded into the system which practitioners will access and enables them to indicate approval on the family's behalf, triggering immediate access to available medical data. The history of consent decisions is recorded to enable practitioners to track when consent is active or has been revoked. The consent framework permits parametrisable consents, for example, name of the requesting local authority, making it a transferable component of SILVER to other projects which seek to digitally record explicit consent and retrieve data. (Appendix 2).

Silver source list

Software has been developed to support the operational function of SILVER, the learning from which could be utilised by future projects wishing to achieve similar outcomes. The locations of the software repositories used to store the source are listed in appendix 3.

Information sharing agreements

Replicable data sharing agreements have been produced which could be utilised for future projects wishing to share health data with local authority services which operate outside of statutory provision. The development of the sharing agreements involved considerable exploration of the legal basis for data processing (Appendix 4).

Clinical risk management

The completion of documents evidencing the clinical risk and tasks undertaken to mitigate risk in relation to the manufacture and deployment of SILVER, will also be of use to future projects working towards a similar aim. Ensuring clinical risk management compliance has been a significant task and demonstrates that SILVER aims to improve the quality and safe delivery of care. (Appendix 5)

Impact upon social care – test data

Findings from our phase 3 listening and development sessions suggest that SILVER could be well received in practice; practitioners perceived access to SILVER as having multiple benefits including: gaining access to information about a parent’s health, validating verbal accounts provided by parents and making information sharing less onerous.

The minimal data entry required to enable practitioners to access the information was highlighted as a strength. SILVER was compared favourably to current systems. Functions such as active/inactive conditions, being able to view the health professionals involved, and the option to view data in two formats; with the preferred method (event log) currently aligned to using chronology that social care services regularly use. Early Help practitioners reported the information sharing achieved by SILVER will provide health information that may better inform family assessments.

Challenges

Whilst SILVER has made progress towards the sharing of health data with social care, data flow is yet to be achieved. Administrative delays have ultimately prevented data flow from occurring, however, there have been a number of difficulties which have also contributed. When the project commenced, the type of health data had not been identified. We explored two possible types and avenues for data sharing which could not be pursued. These were secondary mental health data (not pursued due to low prevalence of secondary mental health care provision within the families accessing early help) and IAPT data held by NHS digital (not pursued as it did not support automated access). Achieving the information governance requirements for the project has been challenging, compounded by the introduction of new data protection legislation General Data Protection Regulation (GDPR) 2018, and the absence of an information governance specialist within the project team. This has resulted in SILVER relying upon external partners, who have demonstrated commitment and goodwill, however are not responsible for the implementation of SILVER. There has been much disagreement amongst specialists as to what is the appropriate legal basis for information sharing in this setting, given that early help provision sits outside of statutory social care intervention. A significant challenge has been time; specifically information governance tasks have exceeding our expectation with regards to the extent of activity and the time taken to complete individual tasks. A further notable challenge in the development of the SILVER system to be highlighted is inconsistency in how data is recorded within GP READ code and the systems used. Whilst this has not contributed to the delay in data flow, it has ultimately affected our ambition for the type of data and way in which this was presented by the SILVER interface to the viewer.

Discussion/conclusion

The sharing of health information to care organisations outside of the NHS is an important development in improving integrated health and social care for the benefit of people accessing services from both sectors. SILVER has achieved the development of a system that is responsive to the needs of practitioners and enables the automated sharing of information between GP practices and social care, where consent has been logged by the patient. The progress achieved by SILVER demonstrates the willingness and capacity of all invested organisations to implement the system, and agree the sharing of GP data with social care. Although data is yet to flow, this is substantial progress towards providing a proof of concept that automated information can be shared, outside of statutory information sharing (e.g. in cases of child protection concerns). To our knowledge, the SILVER care pathway project is the first project of automated health data sharing outside of the NHS to make these achievements. Such information sharing has the potential to improve the care of families.

Future plans/sustainability

SILVER is a proof of concept project. Once signing of the information sharing agreements is achieved, the wording of these agreements could be used to inform information sharing agreements on the information sharing gateway. This would provide a facility for information sharing between multiple GP practices and social care services and identify whether the willingness to share information between one LA and GP practice is present in others. Phase 3 listening and development sessions suggest that SILVER has the potential to have a beneficial impact upon care. To determine effect, SILVER will need to be piloted within one or more LA areas. A pilot of SILVER would inform further care integration and system developments, prior to further testing and wider implementation. Further impact upon care could be achieved by two way data flow, wherein information from early help plans produced by early help practitioners could be shared with GP’s. Consideration should be afforded to the use of MIG data and whether there are any viable alternative data sources which can offer additional analytical functions and increase the likelihood of SILVER retrieving data from a sustainable source. The MIG relies on data being inputted into the GP recording system EMIS, consequently the data presented via the MIG is dependent upon the quality of coding entered by individual GP's. The need for consistency in coding health data is apparent if it is to be utilised effectively (Tai 2007).

The passage of time has opened up further opportunities for the SILVER system. The commissioning of Cerner by Great North Care Record (GNCR) means that if the SILVER system was integrated with the Cerner FHIR APIs (Application Programming Interfaces) other information sources would become directly available over time. The configurability of the SILVER consent framework means that new purpose specific consent types could be created, and the SILVER project's experience with brokering data sharing agreement could be utilised to rapidly facilitate new forms of information flow. Implementation of new data sharing standards (FHIR, SNOMED) and new data sharing infrastructure (CERNER) will likely influence the development of future projects. Learning from SILVER should be shared in a timely manner to ensure the sector benefits from lessons learned and achievements do not become defunct before a system goes 'live'.

Author/Main contact

Dr Ruth McGovern
Institute of Health & Society
Newcastle University
Baddiley-Clark Building
Richardson Road
Newcastle upon Tyne

NE2 4AX

r.mcgovern@ncl.ac.uk

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