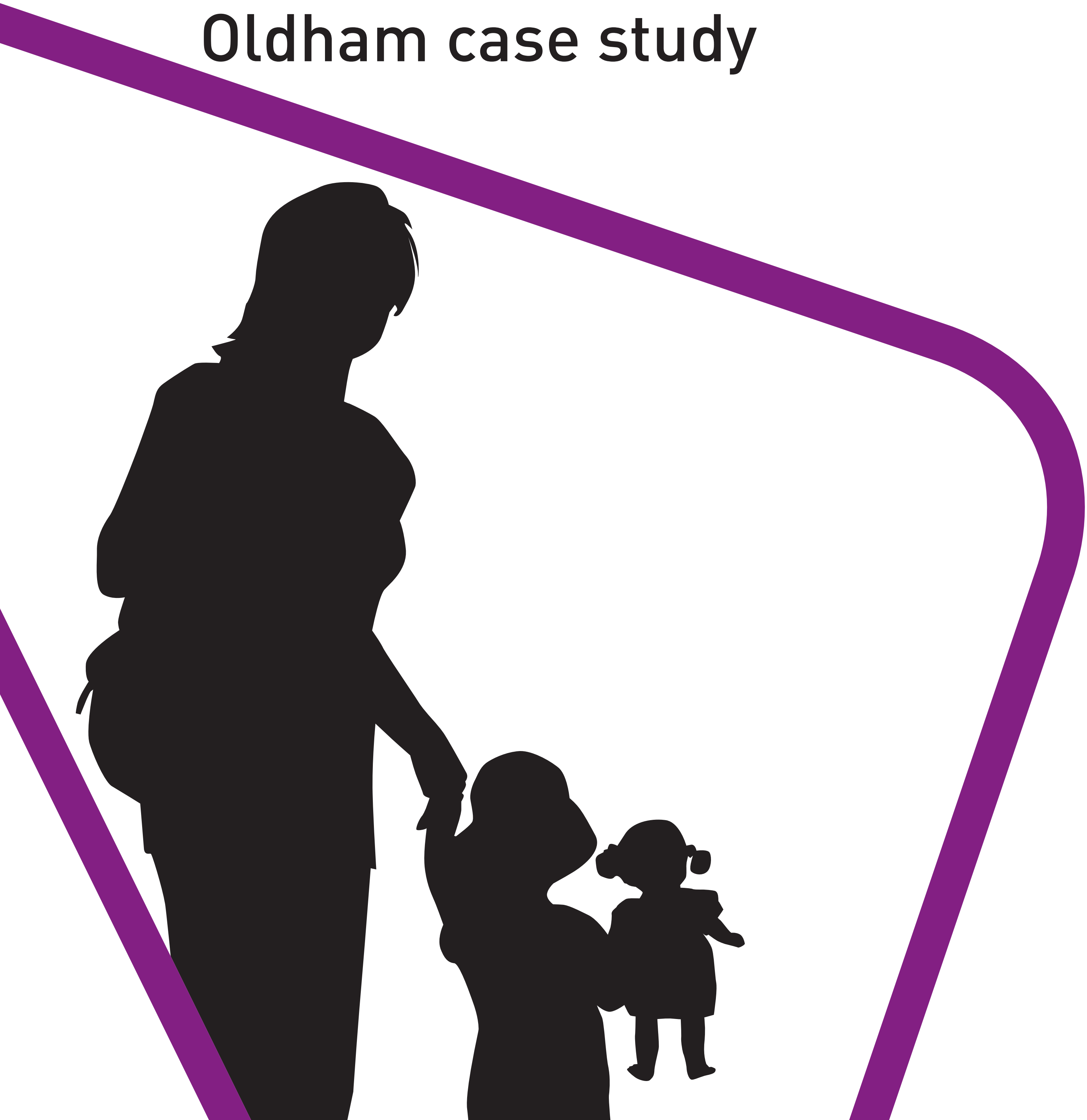
Centre of
Excellence for
**Information
Sharing**

Sharing health data to improve outcomes for families and children:
Oldham case study



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Introduction

The Troubled Families Programme was set up in 2012 to support families with multiple and complex problems. In the past, these families have often been failed by services which have tried to respond to the one problem that presented itself to that service at that particular time – whether it was truancy, domestic violence, anti-social behaviour or unemployment – but failed because they have been incapable of dealing with the many inter related problems the family is facing.

Information sharing has been at the heart of the Troubled Families Programme since it first began. Not only does information sharing allow the most complex and costly families to be identified (by using data to cross reference the demand they are placing on different services), information sharing also means problems can be tackled more effectively. For example, persistent truancy is easier to address when the keyworker knows that a parent has very poor mental health and is struggling to get out of the house themselves.

As the current programme's evaluation is already showing, many areas have made great progress with data sharing, but others still have a way to go and sharing health information has been a problem for some. For this reason, the Department for Communities and Local Government (DCLG) has worked with the Department of Health (DH), the Centre of Excellence for Information Sharing (the Centre), local authorities and health bodies in Staffordshire and Oldham to test new approaches to sharing health information.

As part of this project, the Centre has worked with local services to identify the cultural barriers and enablers to sharing health data and looked to capture good practice which others can adopt. During this work, the Centre identified a number of significant obstacles to sharing information between local authorities and health organisations. Patient confidentiality and legal 'gateways' are crucial factors for health organisations when considering whether to share information and what information should be shared. However, cultural barriers also play a significant role in health's decision when considering whether to share with council-led troubled families teams. There are also concerns around whether health information can be shared prior to engaging with, and discussing information sharing with families and whether sharing this information can be justified on the basis that it would directly benefit families by improving their health needs (alongside tackling other interlinked issues).

To understand this further, Engagement Managers from the Centre (with DCLG and DH support) carried out a series of visits, semi-structured interviews, and supported workshops with key professionals involved in the management and the delivery of both the Staffordshire and Oldham Troubled Families Programmes. This case study reviews the Oldham programme.

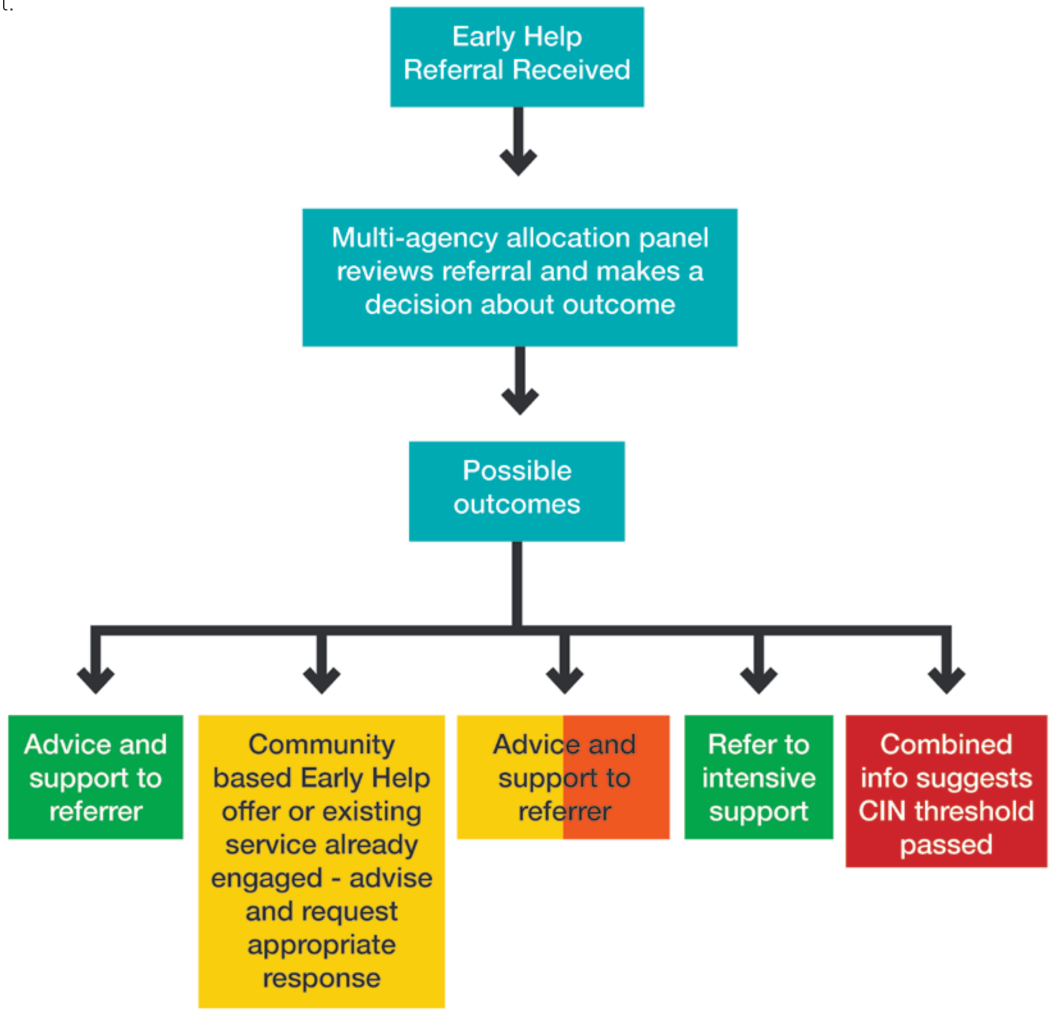
Oldham's approach to troubled families

Within Oldham, the Troubled Families Programme sits within a universal age 'early help' service.

After a year of delivery, the total number of people supported across all areas of the early help service is 4,237 households and 7,595 unique individuals.[1]

Delivered by council-based teams and through contractual arrangements with third party suppliers, Oldham's early help service is targeted at residents who experience multiple and often complex issues in their lives. The different strands of the service are designed to identify these residents, and provide short but often intensive services, with the aim of resolving complex issues before the need for escalation to more specialist services such as social care, mental health and drug and alcohol services.

Developed in 2014, and commencing in 2015, Oldham's early help model takes a person centred approach and is designed to intervene at the earliest opportunity. It covers a spectrum of support from voluntary and community sector networks (e.g. mentors, community advocates, community groups), to professional support through a key worker model.



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[1] Figure taken from: http://committees.oldham.gov.uk/documents/s75160/PSR%20in%20Early%20Help%20and%20Prevention%20Strategy%20-%20November%202016.pdf

To support the provision of early help in Oldham two 'foundational' tools were created:

1) A suite of assessment and planning tools - created to allow practitioners to assess the severity and breadth of presenting issues before planning and delivering subsequent interventions.

2) A data matching tool - a secure solution that controls access to the data inputted at a granular level. The information can then be collated and linked information to support the identification of people who need additional support as part of the early help offer including the troubled families' element.

As part of the early help assessment process, informed consent is sought for all individuals engaged with the early help offer. This supports further sharing of information between practitioners actively involved in the delivery of the early help offer. As part of the Troubled Families Programme, data is also fed into a national evaluation to measure the impact of the programme.

Information collated also supports analysis of demand on public services in Oldham with an aim of improving service delivery for residents. This was achieved through a data matching process accessed by approved members of the Oldham Council Community Services Innovation Team (CSIT).[2] The data matching was done by linking the information within a data warehouse by a secure box method. Any findings from this was aggregated to a place level ensuring no individual or household could be identified. Using this approach Oldham Council were able to identify that half of all demand placed on the system over three years came from approximately six per cent of the population.

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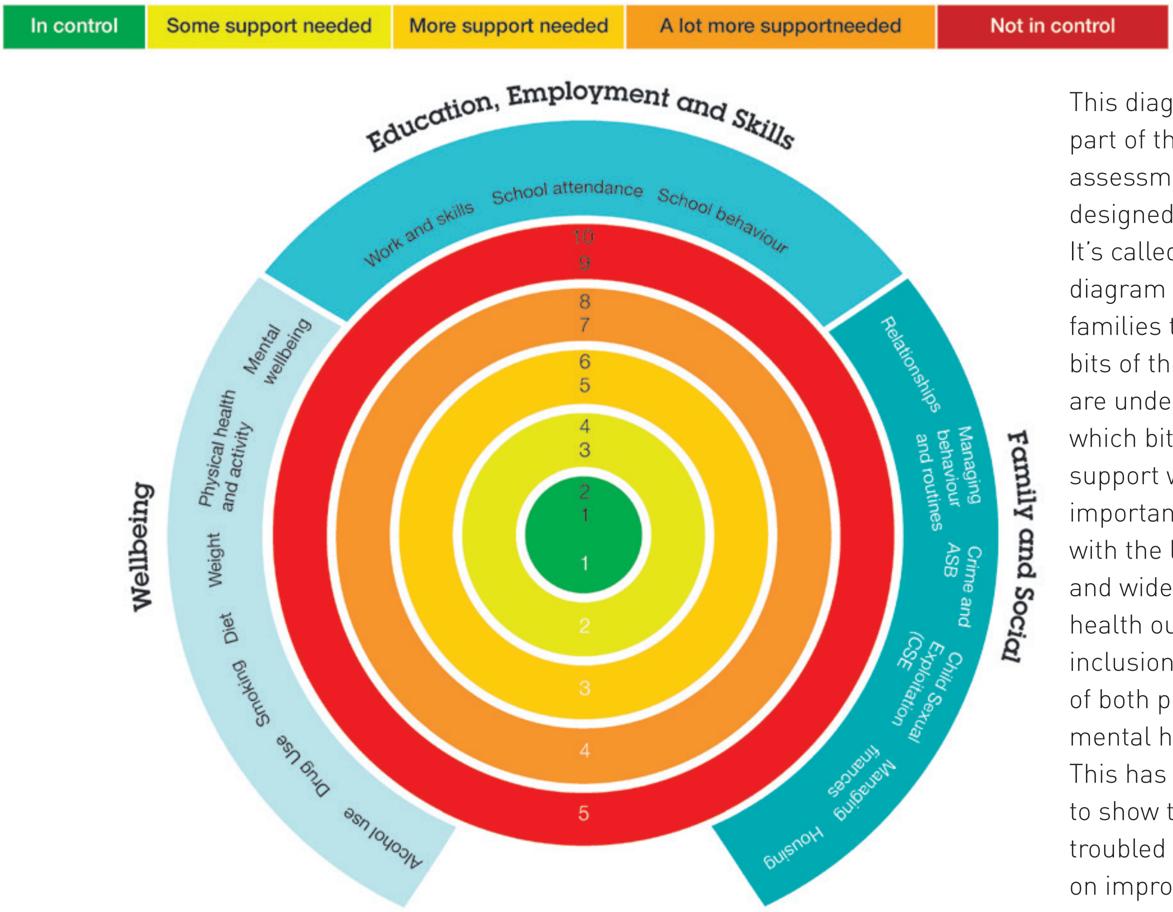
[2] Since the writing of this case study, the 'community and innovations service team (CSIT)' has been disbanded and its functions are being managed by the children's social care and early help directorate (who commission support from business intelligence).

Embedding health in Oldham's early help service

Oldham has pursued a range of different ways to include health needs and health data in their early help referral, assessment, identification, and demand analysis work.

The main strands of this work have been:

- Bringing health and non-health focused services together through commissioning – for example, when setting up the early help delivery team, Oldham identified support and behaviour change services across a broad range of public sector organisations. Enabling them to bring together smoking cessation and NHS health checks services together with services such as parent support, early years' support, and employment support, to form a single early help offer.
- Supporting identification of physical and mental health needs in their assessment process – by creating a wellbeing section in the assessment 'wheel' to enable self-reporting of physical and mental health needs by individuals and families themselves.
- Building strong links with local healthcare organisations – by embedding them as part of the delivery team, developing joint training activity, and encouraging them to make referrals into the early help service.



This diagram is a key part of the early help assessment approach designed by Oldham[3]. It's called the 'In control' diagram and its used by families to indicate which bits of their life they feel are under control and which bits they need support with. What was important for the work with the local GP surgery, and wider analysis of health outcomes, was the inclusion on the diagram of both physical and mental health factors. This has enabled Oldham to show the impact of troubled families support on improving health outcomes.

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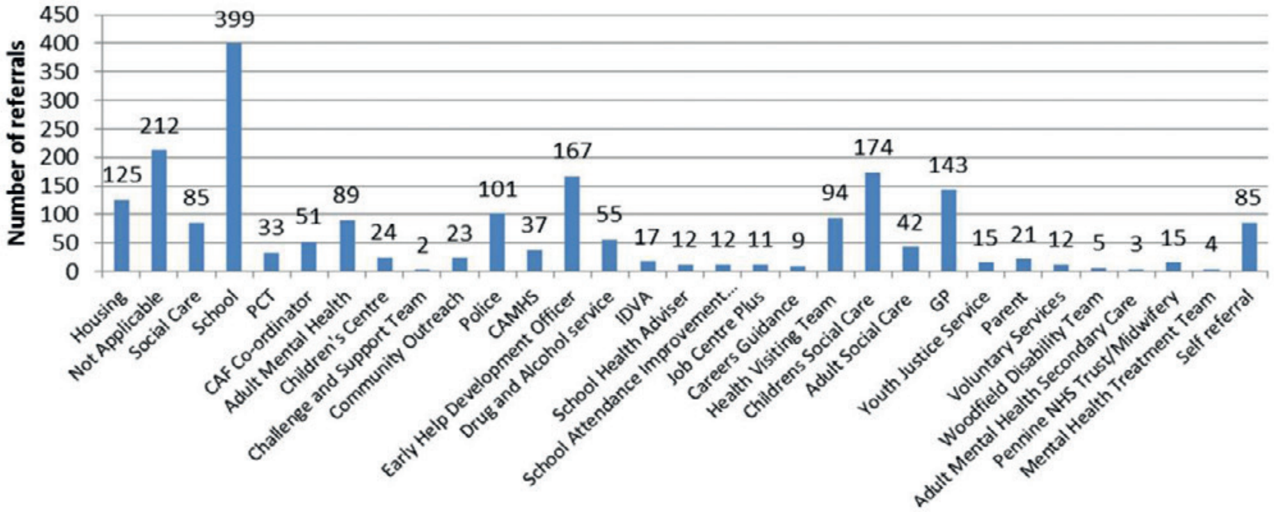
[3] For more information about the 'In control' diagram please visit www.oldham.gov.uk/download/downloads/id/3778/early_help_assessment_and_early_help_services

Joint-training example

Funding from the police and crime commissioner enabled the Oldham early help (EH) team to second two drug and alcohol workers from One Recovery to provide training, support and advice across all the EH teams. Benefits included:

- upskilling EH workers to deliver more substance misuse interventions; and
- the offer for people with substance misuse issues has been increased.

Sources of referrals into Oldham's early help programme in its first year (2015-2016)[4]:



Health information sharing developments in Oldham

Building on the links with local health agencies, and the information sharing infrastructure already in place, Oldham's early help service has also sought to use sharing of health data to:

- enable early identification of families with significant levels of need (including health needs) before they reach crisis; and
- better understand the level of use/demand on local health services over a period of time.

To support information sharing for these purposes, and for its use in the national troubled families evaluation, Oldham Council and its partners have undertaken a Privacy Impact Assessment for the early help service, and published a Privacy Notice on the Oldham Council website[5].

To support health data sharing, relevant health organisations, both local and national, are identified within the Privacy Notice, including Oldham Clinical Commissioning Group, the Health & Social Care Information Centre (now NHS Digital), and other strands of the National Health Service (such as GPs, health visitors, consultants and school nurses).

Data sharing is also supported by seeking consent for information sharing from people identified as eligible for support from the early help service. As a result of these consent conversations around 95% of people have given consent for their data to be shared.

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[4] Chart taken from: http://committees.oldham.gov.uk/documents/s75160/PSR%20in%20Early%20Help%20and%20Prevention%20Strategy%20-%20November%202016.pdf

[5] See: https://www.oldham.gov.uk/info/200148/data_protection_and_freedom_of_information/1402/troubled_families_project/2

The challenge

Despite consent being in place for the majority of people receiving support from Oldham's early help service, the early help team have encountered problems accessing health data. A problem which hasn't been encountered in their data sharing discussions with other services.

The early help team have also recognised that even if they are able to gain access to health data after identifying someone as eligible for support, they may still be missing people who are eligible by not being able to consider health needs right at the start of the identification process.

The approach

As a result of the challenges encountered, Oldham has taken steps to find a solution and improve the health data sharing activity taking place both to identify families in need and to improve their understanding of health need demands in the local area.

Specifically, Oldham have looked to progress this ambition by:

- developing and delivering a data sharing pilot with a local GP practice; and
- engaging with national and local health agencies to gain support for neighbourhood level health data sharing to aid identification and enable health demand mapping.

In the next few sections of this case study we take a closer look at the barriers to information sharing and explore the challenges, approaches, outcomes and learning from the GP data sharing pilot and the neighbourhood level health data mapping.

Cultural barriers to information sharing

Discussions with the council's early help team, community services innovation team (CSIT) and their partners, about the GP data sharing pilot and neighbourhood level health demand mapping in Oldham highlighted a number of challenges to information sharing. The tables below outlines the challenges, the approach taken to overcome these, and the outcome.

Information sharing maturity

Challenge	Approach	Outcome
There was a skills gap in GP practice regarding data extraction (to enable data matching). Whilst the GP practice manager had good knowledge of the data system used by the GP (EMIS), the data sets, and the report functionality, some support was needed from the council.	Support provided to the GP practice manager by the council's staff to ensure that when the data was extracted it was pseudonymised (by the EMIS ID) and that the health data was 'coded' so no-one in the council knew what it represented.	Able to get data in a format which supported matching.
Method used by GP practice to record health indicators did not enable targeting of people with specific conditions.	A generic 'health issue' flag was added to every pseudonymised patient record where health issues were present. This flag covered several different health conditions, which were not specifically identified during the data matching process. This meant that the pilot couldn't be that targeted.	Learning captured about need for GPs to perhaps be more detailed in the way health issues are recorded in their notes, and future data sharing to focus on specific, high priority health indicators, such as diabetes.
Oldham Council are quite mature already in their data analysis and information management capacity – namely, they already had a data matching tool, data warehouse, and approach to consent/Privacy Notices – so when engaging the Clinical Commissioning Grroup (CCG) in the proposed neighbourhood level data sharing activity, they had to take account of the CCG starting from a different point (in regards to information sharing).	Discussion with relevant CCG sub-group to gain a shared understanding of the aims and the agreed way forward.	Joint proposal approved by CCG sub-group and support offered from Data Services for Commissioners Regional Offices (DSCRO) following joint approach.

Organisational complexity

Challenge	Approach	Outcome
Ambition to have access to a large quantity of, and wide ranging, set of health data at an individual level, for use to identify individuals eligible for support (prior to engagement by the early help service) and for neighbourhood level health demand mapping.	Internal review of the long list of health data field (in response to feedback from the troubled families' health information project team that the data is not held by one single agency, e.g. NHS Digital). Refined the quantity of data sets wanted and focused on engagement with Public Health, and then CCG to access this rather than continuing to progress an application for this data with NHS Digital via the national Data Access Advisory Group (DAAG) processes.	Joint proposal for data sharing, focusing on small number of agreed datasets, agreed with Oldham CCG and being pursued with local DSCRO.

Risk and fear / building trust

Challenge	Approach	Outcome
Managing risk when working with personal data concerning vulnerable individuals.	Secure box approach and mapping of processes/data flow as part of partner Information Sharing Protocol (ISP) with GP. Getting feedback on ISP from the Centre of Excellence and the Department of Health also helped in getting GP sign off.	Risk managed and partners are now confident their data is being managed appropriately. Tested ISP structure (developed for pilot area) could be rolled out to support sharing with other local GP practices with knowledge that it has had GP support.
Health partners (in the CCG working group) had concerns about how health information shared might be used and interpreted by the council, without specialist knowledge to understand the datasets in detail and the changes in recording systems over time.	Agreement made between the Oldham Council early help team and Oldham CCG, to involve the CCG in how the early help service uses data, and to have these discussions between both parties at an operational level, before anything is presented to senior officer.	Joint data sharing proposal (using a limited set of health data sets aggregated at community level) agreed with Oldham CCG information sharing working group and being progressed via the DSCRO.

Information governance

Challenge	Approach	Outcome
▶ Developing an information sharing protocol with a local GP practice.	▶ Working collaboratively with the GP practice to design the approach to sharing, and ensuring control of what is shared remains firmly with the GP.	▶ GP is willing to share data for matching and to engage in case discussion for identified individuals.
▶ The potential need to regain consent from everyone in response to queries raised by NHS Digital's DAAG when seeking access to health data. Clarity required on: 1. how long the data is being kept for; and 2. what specific data would be sent to HSCIC (for the purposes of matching). The information in the consent form/notices could be made clearer to the public. For example: • making it clear that you can opt out of data sharing and still get early help service; and • mentioning HSCIC (now NHS Digital).	▶ Changes made to the early help/troubled families Privacy Notice, so it includes: 1. clear statement about how long data is kept; and 2. references to HSCIC (now NHS Digital) as an organisation which may be involved in data sharing. The decision was made that it would not be feasible to re-consent people from earlier periods, unless the early help service are still working with them. (Posting letters could be ineffective due to the low level return that often occurs and potential for people to have changed address).	▶ Considering further steps which could be taken to support the consent process. For example: 1. building in a consent check/update, as part of the current annual review of the early help customer database; and 2. working out if residents understand references to NHS Digital, i.e. who they are, or if further explanation is needed. Considering submitting a revised request to NHS Digital to focus solely on sharing pseudonymised data.

Joint working

Challenge	Approach	Outcome
Responding as effectively as possible to the large number of registered patients identified as having complex needs as a result of the data sharing pilot, when there is limited capacity within the early help service to support them. (The early help service is already handling over 4,200 cases a year, this is significantly more than the 3,000 cases originally envisaged).	Testing of different threshold levels against the sample of matched data from the GP data sharing pilot, to find a point in line with the available resources, whilst ensuring those families with the greatest need are prioritised. Joint discussion of identified cases to identify what support they are already getting and agree if additional support is needed and which agency/programme is best placed to support that case.	Final cohort of 75 people selected with five or more needs (including at least one health and one non-health need) for further consideration through a joint case discussion. The early help service are now supporting a number of these cases where short-term interventions were identified as being able to realise the benefits. Whilst a number of other individuals (from the 75 test cases) who are in need of longer term support are receiving support from the focused care programme (run by GP practice).
Local GP did not always have sufficient information relating to a patient to see the full picture, and/or determine root causes of their problems.	Following the data matching process of the pilot, the GP met with the early help manager in a secure office environment to discuss the selected test cases. These cases were worked through in turn. Discussion started primarily with the early help manager outlining the range of needs known to them, followed by the GP then deciding what health data to share, or not share, in the case discussion.	Both the GP and the early help manager found the sharing of information through the case discussion provided a more comprehensive picture of the patient's need, enabling effective decision making about how these needs would best be supported and by which agency. For example, it was evident that in some cases where domestic violence was a factor (indicated by calls regarding domestic abuse made to the Police) the GP was not aware of this and commented that if they had known they would have worked differently in how they managed the patient's case.

Engagement		
Challenge	**Approach**	**Outcome**
Getting patient buy-in/support for local GP practice data sharing pilot.	Oldham Council worked with GP practice to agree the approach. A notice in a patient newsletter was planned originally, this was changed to a letter to each patient (in response to feedback from GP practice). The content of the letter was drafted by the early help team and the GP practice, with feedback also requested from a DH representative from the troubled families' health information sharing project.	The content of the Privacy Notice letter was agreed and signed-off by the GP practice, who also managed responses. A very small number of people opted out (approximately 50 out of 3,000 registered patients).
Engaging with local health sector partners to get neighbourhood level data.	Review of initial long-list of health data sets prompted discussions with the Public Health team within the council. Support gained from a Public Health consultant with shared viewpoint of data sharing benefits. Joint proposal for data sharing, focusing on small number of agreed datasets, submitted to Oldham CCG's information governance group and discussed at a meeting.	Joint proposal agreed and being pursued with the local DSCRO.

Think family		
Challenge	**Approach**	**Outcome**
▶ Turning individual level data into household level data in order to identify troubled families. ▶ Household amalgamation can be very difficult as the quality of the data from different agencies isn't always good enough to support pooling into household level data. Often this is only seen when you try to match data sets, as the quality of the data is sufficient for its use by the owning agency (when used for their own purposes) but not good enough to support amalgamation.	▶ Using a range of rules, the early help team were able to link data about people, and then apply additional rules to group the data into households. ▶ Matching rules developed by Oldham to maximise the accuracy of the 'grouping process' to identify families. For example, the early help team tested the size of 'families' being identified and spotted a number of 'super families' which turned out to be children's homes, so changed the matching logic to resolve this issue.	▶ Able to identify people with complex needs through the early help programme, ensuring effective delivery of the troubled families element of Oldham's early help programme.
▶ Contacting and gaining consent from registered GP patients (families and individuals) for the data sharing pilot.	▶ The preferred approach was to ensure that every individual patient received a personal letter and request for consent. As the letters went to individuals, families all registered at the same GP practice will have received multiple letters.	▶ Learning point – need to consider how receipt of multiple letters within one family is dealt with/perceived.

GP data sharing pilot and population level data matching

In this section of the case study we take a closer look at the work and learning from the GP data sharing pilot and the neighbourhood level health data mapping.

GP practice data sharing pilot

Drivers

In order to improve the health and wellbeing of Oldham's population, Oldham Council have been looking at ways to increase the resilience of individuals and communities.

In relation to increasing the resilience of individuals, the council and Hope Citadel Healthcare[6] independently developed the early help and focused care programmes. Both programmes have achieved significant benefits on their own, but there was a recognition that a joint programme of work to bring the programmes together could further enhance the benefits achieved.

Challenge

Whilst a small number of individuals with health and other complex needs in Oldham are being identified through referrals by local health organisations (and in some cases self-referrals), there was concern that local people might be missing out on early help due to the lack of health data available for early identification.

There was a need to systematically identify the people who need help early in the lifecycle of a problem to facilitate the provision of care - making it quicker and easier for help to be accessed by residents when they need it, before problems escalate and more specialist help is required.

In response to this challenge, and as part of the planned programme to join up the early help and focused care programmes, a data sharing pilot between Hilltop Surgery[7] and the council's early help service was proposed. The aim of this data sharing pilot was to enable health issues to be considered alongside other troubled families criteria (such as school absence, anti-social behaviour, and worklessness) to identify residents in need of support, without having to wait for a referral.

Approach

During 2016, Oldham Council's early help team worked closely with a local GP practice - Hilltop Surgery, to pilot an approach to sharing data that enables them to identify people whose complex needs could be better supported by either the council's early help service or the 'focused care' programme run by the GP practice (as a member of the Hope Citadel Primary Care Group).

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[6] Hope Citadel Healthcare is a not-for-profit community interest company, who have been commissioned by local CCG's to provide NHS services to the local area where the practices are located.

The company practices "whole person healthcare", working with on-site counsellors, community nursing team, and other external organisations to support patients who often fall between the gaps of social and medical care in a Focused Care approach. Demonstrating Hope Citadel's understanding that good health is not just related to clinical matters but that it is affected by many complex factors such as; social, economic, community issues, beliefs, family circumstances and employment.

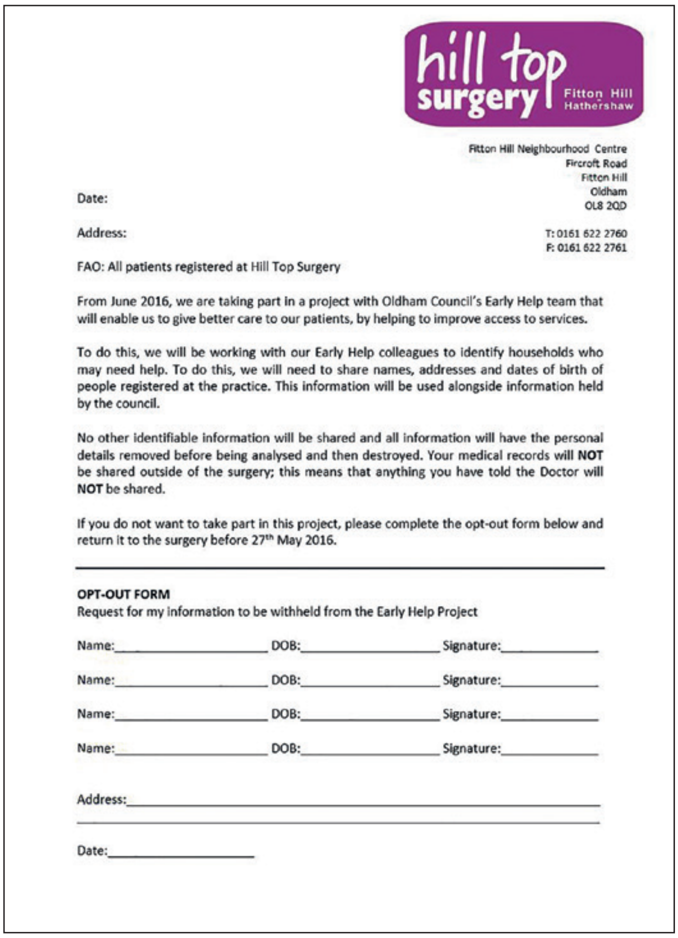
[7] Hill Top Surgery, which opened in July 2009, is one of four GP practices in Greater Manchester that are run by Hope Citadel Healthcare.

Information governance

Staff from Oldham Council worked collaboratively with the GP practice to design the approach to sharing; ensuring control of what is shared remains firmly with the GP.

This was set out in an Information Sharing Protocol (ISP) which was agreed and signed up to by both parties.

The protocol covered not only the technical details of how the data would be shared (through data matching and case discussions), but also set out clearly the purpose for sharing the data, the specific data sets to be shared, and how the GPs patient would be engaged in the process and given the opportunity to opt out.



hill top surgery
Fitton Hill
Hathershaw

Fitton Hill Neighbourhood Centre
Fircroft Road
Fitton Hill
Oldham
OL8 2QD

T: 0161 622 2760
F: 0161 622 2761

Date:

Address:

FAO: All patients registered at Hill Top Surgery

From June 2016, we are taking part in a project with Oldham Council's Early Help team that will enable us to give better care to our patients, by helping to improve access to services.

To do this, we will be working with our Early Help colleagues to identify households who may need help. To do this, we will need to share names, addresses and dates of birth of people registered at the practice. This information will be used alongside information held by the council.

No other identifiable information will be shared and all information will have the personal details removed before being analysed and then destroyed. Your medical records will **NOT** be shared outside of the surgery; this means that anything you have told the Doctor will **NOT** be shared.

If you do not want to take part in this project, please complete the opt-out form below and return it to the surgery before 27th May 2016.

OPT-OUT FORM
Request for my information to be withheld from the Early Help Project

Name:____________________ DOB:____________________ Signature:______________

Name:____________________ DOB:____________________ Signature:______________

Name:____________________ DOB:____________________ Signature:______________

Name:____________________ DOB:____________________ Signature:______________

Address:____

Date:____________________

Engagement

As with the development of the ISP, the council and GP practice also worked together to agree the approach to gaining buy-in from patients.

A notice in the practice's regular patient newsletter, about the planned data sharing pilot, was originally planned but after further discussions with the GP practice the approach changed to a letter being sent out to each patient.

The content of the letter sent to patients was drafted by the council and GP practice, with feedback also requested from a DH representative on the troubled families' health information sharing project.

As the letter was being sent to all of the people registered with Hilltop GP Surgery, it was agreed that it would be sent out by the GP practice itself (rather than the council), and that the GP practice would also provide the point of contact for any questions or requests to opt-out.

At the end of the agreed time period (roughly 1 month), only 50 out of around 3,000 registered patients opted out of the data sharing pilot. The GP practice recorded the opt-out requests received both in a hardcopy file (containing the completed forms, or documented requests) and on an excel spreadsheet (containing name, address and EMIS ID) which could then be used to exclude people from the reports run as part of the data matching process.

Data matching

To carry out the data matching process there was a need for two key data flows of information from the GP practice:

1. a full list of patients (excluding anyone who opted out of data sharing) containing their given name, family name, date of birth, gender, full address, and EMIS ID. This list enabled the patient records to be matched against records so they could be referred to just by a pseudonymised ID (the EMIS number);

2. a list of patients, referred to by just the pseudonymised ID (EMIS ID), listing any health needs in the form of non-descript demand codes (such as GP1, GP2 and so on), which could be matched with the council's records (using the EMIS ID), enabling the council to know where health needs are present without knowing what the exact health need is.

The pseudonymised (EMIS) ID and a list of health demand codes were shared via secure email (using Egress Switch) with the council's community services innovation team (CSIT) for matching against the early help data records at their data warehouse. The fact that the individual was registered at the GP practice was also added to the council's record at this time. To ensure the best quality of results both automatic and manual matching of records was used by the council.

To ensure security of the data shared by the GP practice and the matched data, the data matching was carried out by the council on a secure PC. A 'secure box' approach was also used by the council to ensure that no single person saw all of the data at the same time. So the person who did the pattern matching using demand indicators only had access to the pseudonymised ID list.

This exercise allowed the matching of two sets of pseudonymised data files containing non-descript demand codes for each respective organisation, covering a period over the last six months. Cases can then be identified using pre-defined pattern matching on the pseudonymised matched data. For example, four or more codes from across the file in the last six months would suggest a household requiring support. The actual data behind the codes is not known, the prevalence of the codes is the important element.

In order to identify individuals 'of interest' where a multi-agency case discussion should take place (to decide what support was needed and which agency should provide it) the matched data was filtered by level of demand.

Initially the data was filtered to show individuals who had three or more demand indicators (with at least one health and one non-health indicator). This resulted in a list of over 550 cases, which was too large for further processing.

Filtering the data to show those individuals with four or more demand indicators (with at least one health and one non-health indicator), produced a more manageable group size of 194 cases.

Only for these individuals identified as 'of interest' as potentially benefitting from support from a service, was more detailed information shared, at the multi-agency meeting stage.

Multi-agency case discussions

> **"The case discussion meeting really drove home the point that sharing information between the council and health was monumentally useful. It was obvious after the first five minutes the value of discussing cases at this level."**
>
> Aaron Atkinson, Oldham Council

In advance of the case discussions meeting (between the early help manager and GP) a report was issued to both parties containing a list of EMIS numbers for those individuals who met the required criteria.

Due to the earlier matching process, the EMIS number can be used by both parties to re-identify the people selected and look at their own records for the identified individuals (both in advance of, and at the meeting).

The identified cases are then worked through in turn, with a discussion taking place between the early help manager and the GP. The discussions took place in a secure office. During these discussions each party is in control of what data is or isn't shared in the discussion and what level of detail is shared. The decision to share or not share information is based on the early help manager and the GPs professional judgement, with each case judged on its own merit. Where the professionals felt there was data which would be useful to be shared, but couldn't be appropriately shared at this stage, the discussion was used to explore steps to enable further data sharing. For example, by agreeing to conduct an early help assessment with the identified individual at which point they could ask for consent to further data sharing.

To test the case discussion process, an initial meeting was held to look at a small selection of 11 cases. This sample of cases covered individuals with four or more demand indicators (including at least one health and one non-health indicator). The outcomes for the 11 test case were as follows:

- two cases already open to early help (accepted to early help in the short time period between data matching and case discussion);
- one case of no further support required (but flags recorded on GP record to ensure any ongoing support takes account of needs identified); and
- eight cases being followed up by either a focus care worker (GP practice) or early help worker.

Following the test case discussions, it was agreed that there was benefit in the data sharing taking place, and that the approach should be further tested with a larger sample of cases, but focused on cases meeting a high threshold in terms of need. Therefore, the second, larger set of 75 test cases were selected from individuals with five or more demand indicators (including at least one health and one non-health indicator).

The decision to offer support, and who it would be offered by (early help or focused care) was agreed at the case discussion meeting on a case by case basis depending on the professionals' view of who already has the best links with the family.

Whilst individual level data shared was matched and then shared in this process, the case discussions enabled those involved to look at and consider wider household/family data as part of the discussions.

Result

With only 50 people out of the 3,000 patients registered with Hilltop GP Surgery opting out of the data sharing pilot, the engagement of local people appears to have successfully gained their buy-in for the data sharing.

Through the pilot, a threshold of five or more demand indicators (including at least one health and one non-health indicator) was found to identify people in most need, whilst ensuring that the number of case discussions required was manageable (namely 75 cases). This will enable any future data matching to be immediately targeted on individuals with at least one health demand indicator and at least four non-health demand indictors. When the data matching was carried out, it wasn't possible to match all of the remaining 2,950 people on the patient list, as for those people who hadn't placed any demand on the system there was no data to match.

During the data matching process it was discovered that matching of GP and council records was most likely to be possible for school age children, as there is 97% coverage of this group in the school census record. Where families had younger children, matching was more likely for 3-4 year olds where free child care entitlement was being claimed, and matching was very difficult for 0-2 year olds as the council is less likely to have any data for this group.

During the case discussions, it became clear that domestic violence was an issue in a number of cases, and whilst the GP was aware of this in some cases, they were not aware of it in all cases. The sharing taking place through the pilot therefore proved to be very useful, as the GP could now take account of this in how they provided support to the patient.

Following the final case discussion, a significant number of the 75 individuals whose cases were selected were picked up by the GP practice's focus care team as they could see they needed long-term support, which was best met through the focused care project.

In addition, a number of individuals identified through the pilot are receiving shorter term support from the early help service.

Lessons learnt:

- support provided by the council to the GP practice manager enabled the GP practice to securely and efficiently run the reports required within their own system (EMIS) to provide the council with the data for matching. If this pilot was developed elsewhere, comparable or perhaps additional levels of support would be needed, depending on the IT skills and confidence of the practice manager;
- some key things to include in a privacy notice/letter[8] to local people about data sharing between troubled families and their GP practice:
  - a description of the purpose for sharing data (for example, to help support people with complex needs);
  - details of what data will be shared, between whom, and how this will be managed securely;
  - a clear description of the information rights and responsibilities of the individual, especially if consent is being requested. This should include specific instructions on how to indicate their consent preference, any deadline by which they need to respond initially, and what to do if they change their mind afterwards; and
  - be as clear as possible in the terms and language used, for example changing 'co-work' to 'working in partnership with...'
- not all potential demand indicator data could be matched as key data fields were not always recorded in all data sets. For example, no names are recorded for STRIVE[9] data;
- whilst very useful, the piloted approach to data matching and sharing through case discussions was very time consuming. So future sharing would work better if the selection of cases was more targeted, focusing on local priority health needs;
- the recording of health need 'demand markers' within GP records/data shared for matching may need to be more detailed to enable targeting of cases with specific priority health needs; and
- a key interest for the GP, when sharing information through the case discussions, was being better able to understand underlying root causes – by cross referencing how patients have been presenting/what they've been prescribed with in the past against the council's insight around non-health factors.

Neighbourhood level health demand mapping

Drivers

The assessment of health needs carried out as part of the Joint Strategic Needs Assessment (JSNA) are useful, but only ever go as low as the ward level. This isn't low enough for Oldham's early help team to group together people in a meaningful way with regard to demand.

Whilst a small number of individuals with health and other complex needs are being identified through referrals by local health organisations (and in some cases self-referrals), there was concern that local people might be missing out on early help due to the lack of health data available for early identification.

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[8] The latest advice and guidance on privacy notices can be found on the Information Commissioner's Office (ICO) website. See: www.ico.org.uk/for-organisations/guide-to-data-protection/privacy-notices-transparency-and-control/

[9] 'STRIVE' is an independently evaluated pilot project initiated and funded by the Police and Crime Commissioners Office for Greater Manchester, focused on interventions with victims and perpetrators of standard risk domestic abuse using a multi-agency approach.

Challenges

Oldham wanted to be able to use data about the use of health services across the whole of Oldham, provided at either an individual or six-figure postcode level, in order to:

- help identify people who might benefit from early help but who haven't yet been engaged; and
- better understand the level of health needs in each neighbourhood and the demand being placed on local health services by local people.

Building on the information sharing arrangements for the Troubled Families Programme, and more recently the implementation of the early help offer, Oldham Council has begun to structure a broad selection of both person identifiable and property/community level information:

- individual service usage and demand data; and
- property-based data aggregated to the six-digit post code which can be combined with, for example, MOSAIC or ACORN geodemographic information to further develop socioeconomic behavioural insights.

This second set of data does include some health service usage data from 2012/13 – A&E attendance, hospital bed days, outpatient attendances, alcohol specific admissions, total cost of GP prescriptions and expenditure on most of these items. However, these health service data are no longer available at such a granular level, since implementation of the Health & Social Care Act 2012.

Approach

Oldham identified a list of 28 health data fields which they wished to use for the purpose of identifying people who could benefit from the early help service and analysing health demands. These data fields were identified through a combination of:

- Oldham Council's own research;
- learning from the wider Troubled Families Programme (many of the items were similar to those being collected nationally for the troubled families' evaluation); and
- conversations with local GPs to identify data that they would consider would indicate vulnerabilities and need for support, when combined with other information the local authority holds (e.g. relating to child's attendance and behaviour at school, social care referrals etc.)

Oldham initially considered applying to NHS Digital (known at the time as HSCIC – Health and Social Care Information Centre) to ask the national agency to share individual or six-figure postcode level health data (against the 28 data fields identified) for the whole population. However, due to the long time being taken to consider an earlier application to NHS Digital (for the sharing of health data for individuals already engaged in the early help programme) it was decided not to pursue this route.

Through Oldham's involvement in the national troubled families' health information sharing project, advice was sought on the 28 different types of health data identified as needed by Oldham and in particular, help on possible sources for this data (see appendix two).

Key points from the feedback on the list of health data included:

- not all of the health data identified is held centrally, so in order to obtain this data would require working with a mixture of national and local health bodies;
- primary care data in particular is more likely to be sourced locally;
- the use of thresholds/trigger points for some of the health data fields (for example, number of GP appointments) might help to focus any whole population level data analysis to identify families in need of early help;
- the need to think about the timeframe over which the health data fields would be looked at (e.g. in the last month, three months, six months); and
- the potential difficulty in gathering health data at a 'family' level (for example, number of GP home visits to family members) as it would require a common definition of family, and may also require collating/cross referencing data from more than one GP practice and/or home address as some family members may be registered with different GPs and live at different addresses.

As a result of this feedback, Oldham considered focusing on a smaller set of health data fields, and reached out to their Public Health colleagues in the council to explore their options. With the support of a Public Health consultant who saw the potential value of the proposed health data sharing, they then developed a data sharing proposal for the information governance working group of Oldham's CCG.

This joint data sharing proposal focuses on creating up-to-date accurate health information using aggregated information (aggregated at a neighbourhood level) which can feed into Oldham's existing community analytical model (as outlined above). The following health data sets have been selected for this purpose:

- total population, split into three broad age groups: 0-18, 19-64 and 65 and over;
- total non-elective hospital admissions, annual for 13/4, 14/5 and 15/16;
- total A&E attendances, annual for 13/4, 14/5 and 15/16; and
- distribution of GP registrations by community.

Result

The CCG information governance working group have agreed to work with the early help team to deliver the proposal for sharing of aggregated health population data.

A mechanism for accessing and aggregating the required data at a neighbourhood level has been identified from the Data Services for Commissioners Regional Office (DSCRO), via the CCG, utilising existing tier one sharing agreement.

Once completed, this aggregated health data will help improve understanding of health demands generally but not identification of individuals directly, as it will not entail personal identifiable data being shared with the early help team. However, it will also:

- help identify communities with particular problems, and where a service response is required;
- provide a way to measure impact of community-based interventions;
- generate a map for each practice of where their patients live (showing patient density by community); and
- support the use of already undertaken community asset mapping, helping the practice or the integrated team care for its patients by identifying assets useful to a patient living in a specific community.

Specifically, the early help team hope to use the aggregated health data alongside other information in their data hub to develop demand profiles for communities which can be used to help inform the way in which services are configured in the area and inform service reform across Oldham's public sector (perhaps providing intelligence to, and shaping a local pilot of place-based integrated early help teams).

Lessons learnt:

- health data isn't all held centrally or by one organisation;
- consider focusing on a small set of health data, sourced locally, to start with as this may be easier for health partnership to respond/agree to;
- the use of aggregated health data may be more acceptable to health partners from an information governance perspective;
- when approaching the local CCG consider approaching the overall CCG board, as well as any operational working group, to gain a wider range of views;
- working with the local CCG has opened doors to the provision of health data analysis by the regional DSCRO (not previously available to the council on its own);
- a key driver for the local CCG to explore data sharing was how it could benefit NHS delivery and/or understanding of places, in particular the potential to reduce service demand and costs for NHS;
- there was uncertainty within the local CCG working group about the benefit of looking at health data at such a low (geographic) level;
- the local CCG did not hold any person level health data, and did not have the ability themselves to analyse data at a postcode level; and
- health partners (in the CCG working group) concerns over the potential for misuse or misinterpretation of data by the council was addressed by agreeing to involve the CCG in discussions about how the early help team use and look at data, before anything is presented to senior officers.

What's happening now

GP data sharing pilot

Applying the learning

The learning from the GP data sharing pilot is being applied by Oldham Council to its integrated place-based approach in a number of ways. This has included:

- production of an internal summary report on the pilot approach, outlining not only the pilot methodology but also the underlining hypothesis and legal bases (appendix three), along with potential further application of this risk stratification approach;
- peer-to-peer learning being shared by the Hilltop GP Surgery with GPs in other place-based pilot areas (such as Holt and Lees);
- a new focus on working with GPs along GP cluster boundaries; and
- applying the principles and learning from work in Hilltop to a new piece of work in the Chadderton area - looking at a range of factors which provide a way to identify people who might benefit from early help support (see box below). Helping to reduce demand on GP practices and the Adult Social Care service, whilst also providing a network to support vulnerable people.

Indicators which Oldham are considering using in the roll out of their early help risk stratification approach:

- adult social care contacts;
- adult social care requests for service that were turned down;
- single occupancy of houses;
- repeat A&E attendances;
- repeat emergency admissions;
- repeat GP attendances;
- increasing prescription costs; and
- people not attending GP appointments for significant periods of time.

Learning points:

- Identification of people upstream of the usual entry points into a system requires identification of indicators of chaotic activity (see appendix four) - the thinking being that chaotic activity at low level in several areas if left without intervention could escalate into more expensive intervention or crisis.
- Knowledge from experienced professionals working in the relevant fields and with the target cohorts should be used to identify appropriate demand flags, based on acknowledged factors that can lead to a reliance on specialised services in the future.

Impact and success factors - putting people at the centre of risk stratification

The review of the GP data sharing pilot found that the data sharing mechanism and subsequent risk stratification could find households with unmet need who were at risk of spiralling further, or those who had just managed to stay below thresholds in individual services.

Specifically:

- 52% of the households which were identified as having six or seven 'flags' required immediate intervention but were not already on a 'high level' radar for either partner organisation; and
- the majority of households with five 'flags' were not known to either partner organisation, and required intervention.

Oldham also found that the methodology was one that could be applied to other practices with similar levels of social deprivation and issues, but may need to be adapted amongst more affluent populations or those from one demographic age.

The sharing of information also allowed true multi-disciplinary team working to emerge, resulting in interventions that reached some of the most vulnerable.

Extract from risk stratification and early help summary report:

"Data sharing is a useful way of early identification of households/individuals who might benefit from early intervention. However, the process is only useful when those households identified are discussed and triaged and the most appropriate response and engagement method was identified."

In their reflections on the GP data sharing pilot, and as a result of the information sharing and risk stratification process, staff in Oldham identified the following as key to delivering successful outcomes for people:

- involvement of the right practitioners in the triage process[10] (bringing their professional and people knowledge into the decision-making process);
- the need to have sufficient capacity within the system to deliver the desired follow up to patients/clients identified as in need; and
- knowing which agency/practitioner has the right relationship to get through the door (which varies case by case) as building on existing trust not only provides a good base from which to offer support, but also helps develop a way forward where patients/clients genuinely feel at the centre of the process (as 'cold' calling following data trawling is likely to antagonise and break relationships).

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[10] Households were ranked according to how many flags they displayed against the agreed markers. Households with a higher ranking than three were discussed at a triage meeting between two senior practitioners, one from Oldham Council and a senior doctor. Each practitioner had access to their own systems to review relevant information that would be useful to make decisions about what, if any, intervention was needed.

Wider benefits from the GP data sharing pilot

Whilst the original pilot was focused on data sharing, the application of learning has helped highlight that more than anything there's a need for a more joined up approach. Prompting further action to work more closely with GPs which may not rely solely on data sharing, such as increasing GP referral into the early help service and the development of joint teams.

An example of this has been the success of the early help team in driving up the number of direct referrals from GP practices which don't offer a focused care type programme (mostly for adults under 65 years old). This increase is a result of the early help team successfully 'selling' the benefits of early help to GPs (such as the lack of eligibility threshold for service, it being open to a universal age group, and covering a wide-range of issues). As a result, the early help team are now planning how best to manage this increase in primary care referrals, and considering the use of early help assessments at GP surgeries, with new materials developed to support its use in this way. This new approach will be trialled in the integrated place-based pilot areas in the first instance.

Population level sharing

The joint request for health data by Oldham Council and Oldham CCG resulted in the data being provided in June 2017, demonstrating that the approach worked (of the CCG making a request for the data and data analysis on behalf of themselves and the council), although there was a time delay before getting the data requested.

Oldham Council and Oldham CCG are now expanding the approach, linked to the evaluation of the Thriving Communities programme, and hope to use an expanded data set of place-based health data to measure impact on wellbeing. The request for this expansion includes a statement of willingness for low numbers to be suppressed, to preserve anonymisation of aggregated data.

Appendix one

Oldham's early help data fields being matched with health demand indicators in the GP data sharing pilot:

- early years - children's centres users, funding for 2-4yr olds data;
- community safety, Antisocial Behaviour (ASB) - contact cards given out for ASB by PCSO, and First Choice Homes Oldham (FCHO ASB data (what happened, who, when, where, what, and action taken);
- police data (recorded by property) - no names, 999 calls - call has been made from this house, DV specific calls, organised crime data, crime offenders;
- education - high needs (Special Educational Needs - from school census); school exclusion - date of exclusion, name of child, reason for exclusion; young people 'not in education, employment or training (NEETS), teenage parent, young carers (positive steps);
- substance misuse / youth health - young people substance misuse, drug and alcohol recovery (adults);
- housing - homelessness applications / prevention, rent balances and arrears, restricted dataset on benefit claimants (provided by Department for Work and Pensions for families accessing early help in Oldham only);
- social care - children's (contacts, referrals, child in need, child protection, Looked After Children, Child Sexual Exploitation etc.), adults social care (contacts, referrals, assessment, safeguarding, re-ablement, reviews);
- council tax data;
- early help - referrals, and cases;
- lifelong learning data - used to look at demand/appetite for qualifications (not used for early help); and
- Independent Domestic Violence Advisor (IDVA) data.

Appendix two

Health data sought by Oldham's early help team and potential data sources

Health data sought	Possible data source(s)
GP individual is registered with	Personal Demographic Service (PDS) https://digital.nhs.uk/article/273/Demographics
Number of GP prescriptions	Not available centrally
Number of GP appointments	Not available centrally
Number of GP home visits to family members	Not available centrally
Do not attend (DNAs) for GP appointments	Not available centrally
Immunisations and vaccinations for both two-year olds and five-year olds	Maternity and Children's Data Sets project (MCDS) www.content.digital.nhs.uk/maternityandchildren
Non-attendance at GP where we know other things that suggest they ought to be attending e.g. Mental Health, Learning Disibility, Special Education Needs (MH, LD, SEN)	Not available centrally
Started on new medication in the last six months	Not available centrally
Missing smears	
Long-term condition diagnosed in last six months	There is likely to be some information available on Hospital Episode Statistics (HES) where patients have been referred by their GPs – but nothing from primary care; may also be local disease registers (e.g. cancer and diabetes)
Adults suffering mental health problems (clinical diagnosis)	For adults who have been referred information may be available from the Mental Health Services Dataset (MHSDS): www.content.digital.nhs.uk/mhsds but nothing centrally for patients who are being treated solely by their GPs
Children suffering mental health problems (clinical diagnosis)	As above - www.content.digital.nhs.uk/CAMHS
Number of referrals to a mental health treatment service	www.content.digital.nhs.uk/mhsds www.content.digital.nhs.uk/CAMHS

Health data sought	Possible data source(s)
Number of people open to a mental health treatment service	www.content.digital.nhs.uk/mhsds www.content.digital.nhs.uk/CAMHS
Number of contacts with a mental health treatment service	www.content.digital.nhs.uk/mhsds www.content.digital.nhs.uk/CAMHS
Adults dependent on alcohol (clinical diagnosis)	Not sure this is collected centrally – though HES and MHSDS may include some relevant data items
Adults dependent on non-prescription drugs (clinical diagnosis)	May be available from the National Drug Treatment Monitoring System (NDTMS): www.ndtms.net/default.aspx
Adults receiving treatment for dependency on non-prescription drugs	NDTMS
Young people having substance misuse issues that reach threshold for structured treatment	NDTMS
Number of contacts with a drug/alcohol service	HES/NDTMS
Number of contacts with a drug/alcohol service	HES/NDTMS
Number of adults receiving treatment for alcohol dependency	HES/NDTMS
Adults and children who are overweight	Not sure information is held on adults centrally – though HES may include some relevant diagnosis codes where a referral has been made. For children: www.content.digital.nhs.uk/ncmp Though LA PH team should hold data about children in its patch
Under 18 conceptions (15-17s)	www.content.digital.nhs.uk/maternityandchildren
Inpatient stays - planned and unplanned (number in total)	HES
Length of inpatient stays - planned and unplanned (in days)	HES
Number of times attended A&E	HES
Number of hospital outpatient appointments	HES

Appendix three

Legal considerations

The following list sets out the legal bases for information sharing identified by Oldham, in relation to their early help risk stratification and monitoring activity:

- Section 251B (Duty to share) of the Health and Social Care Act 2012 (amended 2015) provides a basis for information to be shared between health services and adult social care where this will facilitate care for an individual. It encourages health organisations to consider the information that can and should be shared in the best interest of the patient.
- Section 31 of the Health Act 1999 makes provision for NHS and local authority bodies to engage in activities that are health related if it demonstrates improvement in the way the functions are delivered. This includes the provision of individual services to individuals.
- Section 82 of the National Health Service Act 2006 sets out a duty to co-operate between NHS bodies and local authorities to secure and advance health and welfare of the people of England and North Wales.
- Section 1 of the Localism Act 2011 gives local authorities a general power of competence which can support further sharing information internally and/or with other legal gateways.
- Section 111 of the Local Government Act 1972 gives local authorities the power to do anything which is calculated to facilitate, or is conducive or incidental to, the discharge of any of the functions of a local authority.
- The Data Protection (Processing of Sensitive Personal Data) Order 2000 No417 4(b). The processing is necessary for the discharge of any function which is designed for the provision of confidential counselling, advice, support or any other service.

Appendix four

Measures of chaotic behaviour used in Oldham's GP data sharing pilot

Direct measures of chaotic behaviour:

- Attendance at Accident and Emergency Departments (AED) – the very nature of AED attendance should mean that something significant has happened, however if attendance at AED is occurring for non-medical emergencies then this is a good measure of a response to chaotic or out of control living.

- Police call outs to property – for the police to be called out there is an incident occurring. Police call outs to property frequently result in no action being taken and police defusing the situation there and then. In policing stratification call outs for low level reasons do not meet criteria for further intervention. However, these incidents could be indicators of relationship difficulties, unstable households or interplay of other families.

- Safeguarding plan in place - children or adults identified as having a safeguarding plan in place are by definition vulnerable, however, it is not standard process for GPs to be informed if safeguarding has been instigated. This marker was one that became the most significant for ongoing recommendations as a result of this pilot.

Proxy (indirect) measures - other measures that were identified by experienced professionals as having potential to indicate chaotic factors:

- Failure to get baby and childhood vaccinations. There has been much spoken in the press about choice regarding baby and childhood immunisations, however medical evidence is unequivocal that these vaccinations are necessary, save lives and prevent long term morbidity. Professionals felt that parents in this particular demographic were unlikely to be choosing not to have their children vaccinated on an informed basis but more likely because they were disorganised and had not attended the appointments or they had misinformation. Failure to complete vaccination programmes is a good proxy measure.

- GP not seeing patients under five - it is unusual for children under five not to be seen by a GP, they get significant numbers of minor illness and complaints and so not seeing the GP in a year for an under five could be a proxy measure.

- Failure to pass or attend two-year-old assessment - although not reaching a satisfactory stage of development at under two is not uncommon, this combined with other proxy measures could be.

- Repeated 'did not attend' (DNA) for appointments - making appointments to see the GP or primary care staff and then not turning up can be interpreted as a sign of wanting support but not being in a position to carry this out.

- Missing/irregular school attendance should be seen as a sign of other underlying problems.

- Contact about household to social services - intelligence/concerns may be passed onto social services but the incompleteness of the information takes it below the threshold for intervention.

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