



Digital & Data - Integrating Third Sector in Leeds Health & Care (LCHP) System

This paper, produced by Forum Central for LHCP Core Development Group, aims to provide a summary of the current workstreams and the Third Sector's level of involvement, and to give Forum Central's view on progress, challenges and the blockages requiring urgent collective action. The appendices provide context and further detail, and work undertaken by the Third Sector with city partners over recent years is summarised below.

Key aspects - what we mean by Digital & Data

- Digital integration (data infrastructure & business intelligence) - fundamental to delivery of ICS & Leeds LCHP
- Data sharing (organisational & service data; person/patient data)
- Digital inclusion/capability (Third Sector & patients/citizens)

Person focused and **service/organisation focused** data are both big issues, but for different reasons and with different associated complexities:

- Person focused: e.g. permissions/sharing clinical/confidential patient information across organisations within a health system to join up their care
- Service/organisation: e.g. organisations/individual practitioners working in this complex health and care system being able to share /find up to date service level information.

What we know - Key building blocks/work programmes where Third Sector integration is needed:

NHS

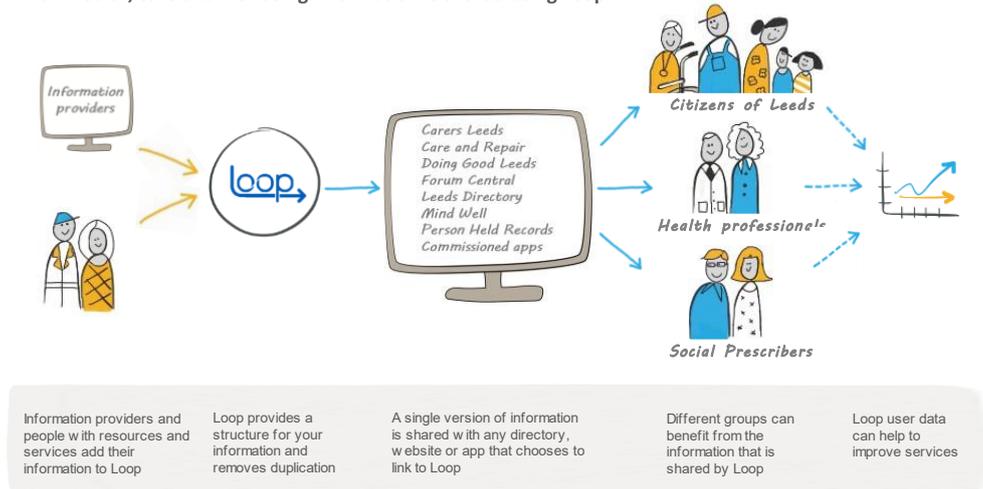
- Health Strategies: e.g. Mental Health Transformation - a five year strategy has been developed with workstreams which has flagged absence of Third Sector digital/data Leeds Draft PBP/HCP Plan notes the shared approach to business intelligence, data infrastructure and governance (Enabler - Data), and the need to develop better connections to the Third Sector

- Commissioning data – data held for commissioning, improvement, outcomes, etc. purposes (e.g. LCPs, PCNs, Population Boards, Sub-groups, Committees) has not been routinely collated and shared
- The national Directory of Services is the central back-end repository of NHS information (mainly used by professionals through [NHS Service Finder](#)).
- The NHS App is increasingly going to be the front door for access to health and care information, both of services available and suitable for them, as well as their own information, held by their GP (used by patients/citizens).
- Clinical templates are used by clinicians in clinical settings to signpost and refer patients, it is/was managed at CCG level. Our understanding is that this includes core commissioned services but does not include small, local-level support and that that type of support may only be highlighted through social prescriber intervention
- Leeds HCP Development Plan & CDG Workstreams flags Digital (enablers) and Third Sector Development explicitly, as well as digital/data implicitly in other workstreams.

LCC

- Leeds City Council is leading on some of the Integrated Digital Services work for the new Digital Strategy - workshops are being held throughout Dec and Jan. It is an iterative process so unsure when they see it as being 'finalised', and where is the Third Sector opportunity to inform developing recommendations
- LCC platforms are migrating onto Drupal - the timeline of how long that will take is unknown. Concern that the direction of travel is to bring everything 'in house', that we lose the expertise of the Leeds Open Online Platform (LOOP) digital contractor, Ayup (who are local to Leeds) who have built up significant experience over the last few years working with other local authorities (Kingston, Hounslow) on platforms based on the same open source code. See below for more information on LOOP
- Leeds Directory is currently the place for information on health and care support services, and would be the main front end/surfacing information stored within LOOP

How health, care and wellbeing information is shared using Loop



- JSA: Third Sector has been involved in the latest version, and also expects to be actively involved in the next stage of work to develop a “live” system.

City-wide data: do it once

Can we create/provide Third Sector organisation/service data in one place that can be used with IDS and partners across:

- Improving the Health & Wellbeing of all our citizens
- Delivering Inclusive Growth
- Tackling Climate Change.

Practitioner-held record: Leeds Care Record

Third Sector needs to have access to it (IG)

TS doesn't only need read access, e.g.:

- Where TSOs are commissioned to deliver health & care services
- Where TSOs are providing other support/touchpoints which impact/contribute towards improved health outcomes, these need to be entered for the benefit of health & care colleagues
- In order for the patient/person to take a more proactive approach to their care & wellbeing, they need to be able to see the whole picture (statutory and non-statutory support)
- Data access works in both directions, i.e. where people may disclose information to Third Sector staff that is not for wider sharing (subject to safeguarding, etc.).

Person-held record: HELM

In development since 2019. Has been paused but now seems to be moving again; limited third sector involvement to date, conversations took place in the early stages but nothing substantial.

Third Sector: current work

Principles adopted by Forum Central in current data collection & mapping work underway funded by HPoC and LHCP (Appendix 5):

Whilst the mapping activities are different, with different aims and outcomes, three themes emerge:

- 1: Data/assets should be searchable against a range of criteria suited to different audiences and needs
- 2: The intention in most cases is to develop an accessible resource with an easy to use front end such as a map/dashboard. This will allow users to produce maps, reports or datasets based on relevant search criteria for different their purposes.
- 3: Attempts are being made to map assets using different levels of data. These are:

- **Funding and commissioning information** - only relevant to the third sector infrastructure partners, and statutory and health partners. Of high importance in terms of parity, fairness, equality and promoting diversity and addressing underrepresentation of community groups within the sector.
- **Higher level sector information** - this is mainly information about organisations, what they are focused on (including type(s) of service user(s) and geographic footprint) and who they work in partnership with.
- **Local trusted information** - this includes service level information and referral mechanisms (i.e. formal/informal) which are relatively stable, for example some details might change once a quarter but most of its information applies year round.
- **Granular, micro level information** - this is the kind which would be almost impossible to keep up to date, things like one off events, which are better shared in newsletters, emails and Facebook groups.

Appendix 4 visualises the Third Sector data and mapping systems, with links to LCC, NHS and other Third Sector partner's workstreams.

A reminder of the Leeds Third Sector size and range of organisations

- Registered charities directly related to physical/mental healthcare services: **170**
- Registered charities contributing to the wider determinants of health: **1,010**

- Micro charities (<£10k pa): **545**
- Small charities (£10k-<£100k pa): **535**
- Medium charities (£100k-£1m pa): **297**
- Large charities (£1m - <£10m): **62**

- Major charities (£10m+): **12**
- Third Sector workers: **9,650**
- Third Sector trustees: **8,600**
- Third Sector volunteers: **40-70k**

Work in progress

- There are different asset mapping exercises taking place (LCPs, Social Prescribers @ Linking Leeds & PCNs are informally gathering data for team sharing, LCC-funded Third Sector Community Care Hubs, LCC Communities Team on Localities/Housing consultation tool Your Voice to gather asset info) - Forum Central are aware of the overlaps, and are trying to protect TSO time/efforts by aligning work to avoid duplication.
- Substantial work on information governance to ensure TSOs meet the standards required to access the Leeds Care Record has been paused - several TSOs have already made significant progress and are at compliance stage but have yet to be given access - Dani Mistry Principal Information Governance Officer, LCC) who has been leading this work is only in post until 5th Jan, which will be a significant loss
- (see digital integration and outcomes in Appendix 1, from draft Forum Central Digital Strategy paper, development of which has been sporadic due to the shifting environment.)
- Work on LOOP has been paused, but the underlying need for a robust data sharing mechanism and platform is crucial if we are to work more effectively together, invest responsibly and implement a model which meet the aims of Leeds strategies and development plans. Directories and information sharing is nothing new and will need to happen whether it's through Loop or another project. The Third Sector are an integral stakeholder in whatever that looks like, as a large user group, so ensuring whatever solution is invested in is co-designed and produced by the third sector is crucial.
- CRM system Civi - alignment in future direction of travel with VAL/TSL (this CRM system is currently used by VAL; Forum Central will be purchasing Civi in 2022 for its own CRM data)
- Workforce development - joint third sector training programme
- CMH Transformation is an example of need for fundamental sharing to enable true transformation/partnership working at community/LCP level to occur effectively

Challenges & blockages

- Potential loss of third party expertise, capacity and pace, e.g. Ayup on LOOP development, at a time when LCC is experiencing capacity issues, but demand for services and for their integration is rapidly increasing

- LCC platforms are migrating onto Drupal, but the timeline of how long that will take is unknown. Concern that in bringing everything 'in house', that we lose the expertise of the LOOP digital contractor on platforms based on the same open source code
- Capability and capacity in the Third Sector: potential loss of staff and associate knowledge where information is not captured in data systems, particularly with organisations making redundancies, or staff leaving the third sector in the current climate
- Staff turnover at LCC/CCG: Forum Central has found it difficult to maintain momentum on digital/data projects given the time needed to establish and maintain relationships with key staff and decision-makers
- Lack of Third Sector representation in city digital strategic group and IDS
- LOOP has funding allocated for its development from the Better Care Fund, but has been paused. The funds are being held by IDS in a 'combined pot', until LCC make decisions about what to fund, which we assume will come after the development of the digital strategy, and the outcomes being committed to which come out of that
- There is a combined 'general' pot of money that IDS has control of that is capital Better Care Fund money - but this is the last year of BCF so it is being used carefully
- In-depth third sector knowledge and understanding is not present or systemically connected to the work of the Integrated Digital Service or Digital Strategy: third sector representation/influence/insight/consultation is regularly sought, but in piecemeal ways

This is causing ongoing difficulties in building trusted relationships between the Third Sector and its LCC/NHS partners.

We recognise that certain investment decisions like LOOP have been delayed until digital strategy is ready, but this will then impact adversely the Third Sector in the following critical ways:

- Our ability to execute the Third Sector role in the citywide digital strategy
- This in turn affects our own ability to provide a useful current and comprehensive directory and asset map for our sector's own needs
- The delays have also meant various third sector partners and networks have begun to resource and produce their own data solutions, which have little to no chance of longevity or impact.

Most urgent of those blockages

Future of LOOP:

- We have been pressing Nichola Stephens and Rob McNally for a LCC decision on the future of LOOP, as the Ayup digital development/support contract ends in January
- Whilst we still haven't received formal confirmation, it seems apparent that a solution mirroring LOOP will be developed in-house by LCC as part

of its Leeds Directory and or LCC website using Drupal

- It is imperative that the Leeds Third Sector is part of this development so that it meets the needs of Third Sector users and practitioners
- Therefore, we need to begin work on a clear joint implementation plan asap.

Leeds Care Record:

- Dani Mistry, Principal Information Governance Officer, LCC has been leading on Third Sector integration/IG work and leaves on 05/01/22; we need clarity on our point of contact and level of engagement in the Leeds Care Record for meeting Information Governance standards/access to Records
- The Third Sector organisations that now meet the standard should be granted access to the LCR (Appendix 1, page 7).

Digital Strategy & IDS:

- We need meaningful Third Sector involvement to influence and shape strategy at this critical stage.

Appendix 1

Excerpt from Forum Central Digital paper, "Digital Enablement of the Third Sector in Leeds" (November 2021)

"Drawing upon recent examples of digital work within the Third Sector and citing current strategic drivers, this paper provides a case for the development of a cohesive digital strategy which recognises and addresses current inequities faced by the Third Sector. With a particular focus on digital integration of the Third Sector, as a means of achieving sectoral and broader system objectives, the paper provides an update and refresh on a draft document shared with city leaders in May 2021.

This paper highlights progress and learning to date, and exposes significant risk factors imposed by a lack of support around digital enablement within the Third Sector."

3. Digital Integration

Digital integration is a foundation stone of joining up health and care service. Developing a digital infrastructure which is inclusive and flexible; achieving consistent levels of compliance around Information Governance (IG) across the broad health and care system; and embedding data sharing in how we operate is essential if we are to achieve shared visions set out in strategy.

Since June 2020, the City Digital Partnerships Team, which is hosted in Leeds City Council has commissioned and funded a Principal Information Governance Officer (Dani Mistry) to work with Third Sector organisations, delivering 'direct care' around Information Governance (IG). Supported by Forum Central the project aims to prepare and support organisations to apply for access to Leeds Care Record (LCR). Working with an initial cohort of 13 organisations identified as delivering 'direct care', (based upon assessment criteria to access LCR), Dani has conducted an IG audit on each organisation. Following the audit Dani has assisted organisations to complete the NHS Digital [Data Security and Protection Toolkit \(DSPT\)](#) providing evidence for data protection compliance. Organisations who successfully progress through the IG audit, and have all the prerequisites for the LCR application have been supported to complete the LCR application.

Project Outcomes:

The project has provided a better understanding of IG compliance within the Third Sector, including examples of organisations which have exceeded expected standards within the DSP Toolkit.

It has also highlighted a significant gap in IG support for Third Sector organisations, seeking to integrate their work with other parts of the health and care system.

Two organisations have been given approval to access Leeds Care Record, through the Leeds Information Governance Steering Group (LIGSG), neither organisation has been granted access due to a decision not to develop Third Sector specific Role Based Access Controls (RBACs).

Four organisations have made applications for NHSmail with support from Dani, each completing the DSPT and receiving advocacy from Dani. Unfortunately, only two of the four were granted access.

All organisations have demonstrated improved IG compliance.

The aforementioned project, is one of a number of projects, some of which involving the Third Sector which has been monitored under the personalised care steering group, digital sub group which promotes connections between services, but also supports people to self-advocate and self-manage their health and wellbeing. This work includes:

Leeds Open Online Platform (Loop): led by The City Digital Partnerships Team. Through Loop, third parties including third sector organisations can build their own websites and systems that connect to Loop and form part of a shared information repository. This work is currently paused, however significant work is being undertaken within Forum Central and Third Sector partners to progress project objectives.

Helm- Person Held Record: Verified citizen access and contribution to an integrated view of their health, care, wellbeing and government services information to support and promote improved awareness and self-management.

The Helm objectives are:

- Helm users able to access and edit their shared support plans in Helm and share them with their health and care providers
- Helm to host a questionnaire
- Helm users have access to structured data from the secondary care
- Identify and trial integration with the NHS App
- Implementation pack to support the regional roll out.

Helm is currently paused.

Curated apps Library: The Curated Apps Library will signpost the citizens of Leeds to apps which are aligned to local health and care priorities and which have been tested to ensure that they are clinically safe, effective, user-friendly and use data in a safe manner. The library will also provide health and care professionals with the reassurance they need to signpost citizens to a suitable app that will meet their needs.

The status of the curated apps library is unknown

The learning amassed from the above projects and their current status raises significant concerns around the implementation of digital plans within the city. It has also highlighted a disconnect between NHS strategic plans and the resourcing and implementation of digital projects. This disconnect poses a significant risk to achieving the city's strategic vision.

4. Strategic development

Since developing the initial Digital Enablement paper shared in May, Forum Central have informed the development of a West Yorkshire and Harrogate Digital Strategy, through the West Yorkshire and Harrogate Digital Board. It is not known what the current status of this document is.

The City Digital Team in Leeds are currently leading on the development of a cross sector digital strategy for the city, with involvement of the Third Sector. Themes are around Primary and Community Healthcare, Supporting Place Ambitions and System-wide working. Consultation workshops around this strategy development will be taking place across December and January (see appendix)

6. Discussion

The translation of Third Sector and broader system support and services to digital platforms during the covid 19 pandemic has highlighted the significant inequalities around digital access, capability and confidence within communities and within Third Sector organisations who support them. The need to work as a coordinated system, to meet the challenges of Covid have also exposed significant inequalities across the health and care system. With the Third Sector seen as providing a key role in a new, personalised, holistic and joined up health and care system which keeps people well for longer within communities, these digital inequalities must be addressed.

The development of inclusive systems which enable the sharing of information between staff across the health and care system, would provide a foundation stone which supports transformation to joined up system working across sectors. Moreso, it would provide routes to reduce the gap between people and services; connect intelligence from communities via the relationships with people, Third Sector organisations work is built upon.

The projects referenced within this paper, demonstrate the wealth of activity the Third Sector in Leeds has engaged and delivered over the past two years; and the learning which has been amassed. We have witnessed a number of these projects been hampered by blockages within parts of the established system, particularly around Information Governance, but also the absence of a citywide plan to enable Third Sector partners to overcome barriers to joined up working. Progress on the development of citywide digital strategy, since the previous

iteration of this paper is welcomed (see Appendix 2). There are however ongoing concerns around the disjuncture between new developments and previous digital workstreams involving Third Sector partners.

In order to achieve a shared digital vision for the city, which embraces assets within the Third Sector, there needs to be a commitment to collaboration and joined up working from across the health and care system. This commitment must be built upon an understanding of Third Sector assets and deficits.

7. Recommendations

Drawing upon learning from across the workstreams outlined above, Forum Central proposes the following recommendations for future digital work in Leeds:

- Identify resources to enable Third Sector organisations which have committed resources in support of digital integration to achieve previously agreed outcomes (specifically in relation to Leeds Care Record and Loop)
- Continue with the co-production of a comprehensive, coordinated digital strategy for the city, with input from all system partners. This should:
 - Include diverse voices from the Third Sector and the people and communities of Leeds.
 - Take an asset-based approach building upon progress, and learning amassed to date.
- Address disparities in Third Sector digital infrastructure and support, through investment in roles, leadership, training and resources which are accessible to, and embedded in the sector as a means of achieving parity.

8. Key Considerations and Risk Factor

The focus of this paper has been digital integration of the Third Sector within the Leeds Health and Care system. It is however important that integration plans are developed as part of a cohesive digital plan for Leeds which recognises broader priorities for the third sector. Key considerations include:

- Work should support measures to maintain the scope, diversity, capacity and sustainability of the Third Sector in Leeds.
- We must invest in work which breaks down silo-based working across the health and care system and cultivates relationships between those working in the Third Sector and the mainstream health and care system.
- Consideration of the impact of overarching system change (particularly the shift of power to the Integrated Care Partnership and Integrated Care System on long term digital strategy, and what that means for Leeds based third sector organisations.

- Third Sector organisations have proven that they are an essential component of the health and care system across the Covid-19 pandemic and before, despite significantly lower digital capabilities compared to other sectors and minimal resources.
- We must ensure that the experiences and voices of Leeds people continue to be at the heart of the work. How does this make it better for people in Leeds?

Appendix 2

Information from State of the Sector report on the Third Sector in Leeds for Health & Care 2020

Funder: Leeds NHS CCG

2018	2019	2020
Yorkshire Ambulance Services NHS Trust £8m Mental health learning disabilities £6m Other smaller contracts £30m	Yorkshire Ambulance Services NHS Trust £30m Mental health learning disabilities £27m Other smaller contracts £178m	Yorkshire Ambulance Services NHS Trust £33m Mental health learning disabilities £29m Other smaller contracts £204m
TOTAL - £44million	TOTAL - £235million	TOTAL - £266million

[1] <https://www.leedsccg.nhs.uk/about/annual-report-and-accounts/>

Appendix 3

NHS England ICS Guidance

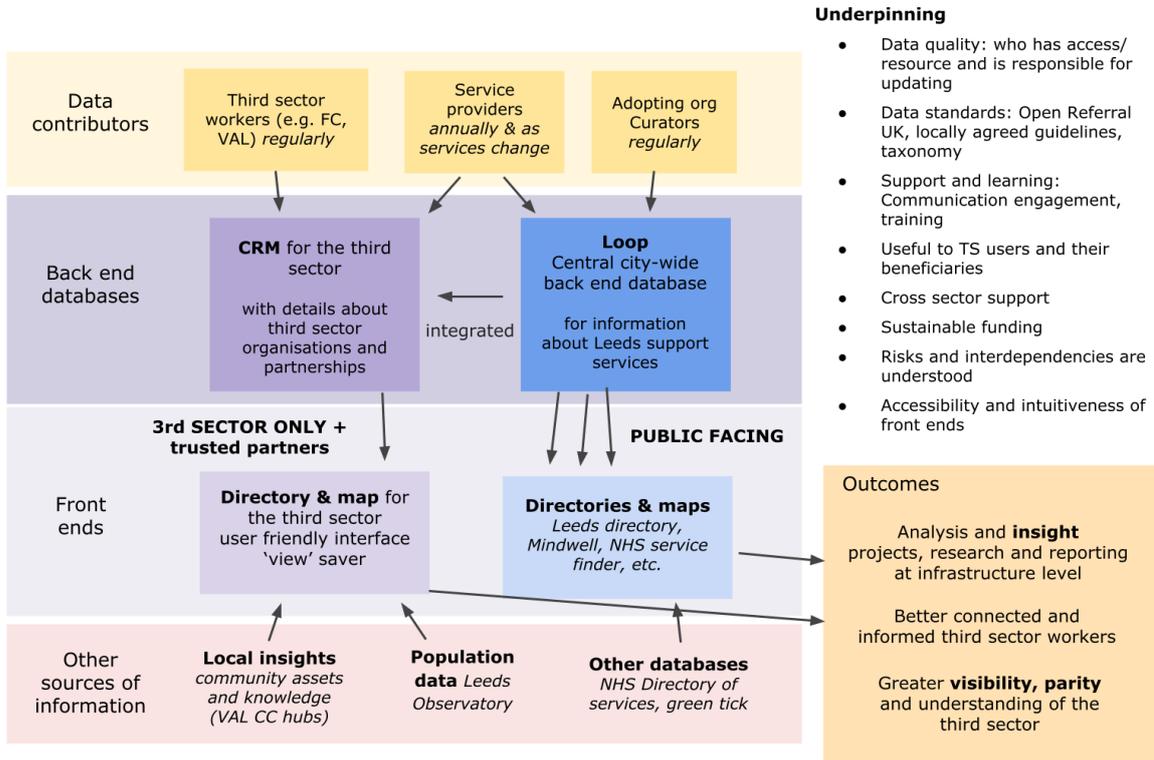
Embedding the VCSE sector in the ICB's governance and partnership arrangements – a checklist

- *System-wide engagement*
- *Asset mapping*
- *Tackling Health Inequalities*
- *Board & network representation*
- *Data sharing*
- *Social prescribing*
- *Wider/social determinants of health & NHS/LCC/VCSE partnerships*
- *ICS support for sustainable VCSE*
- *Commissioning VCSE*
- *Non-financial support*
- *Measuring impact & social value*
- *Volunteering strategy – public & VCSE sectors*

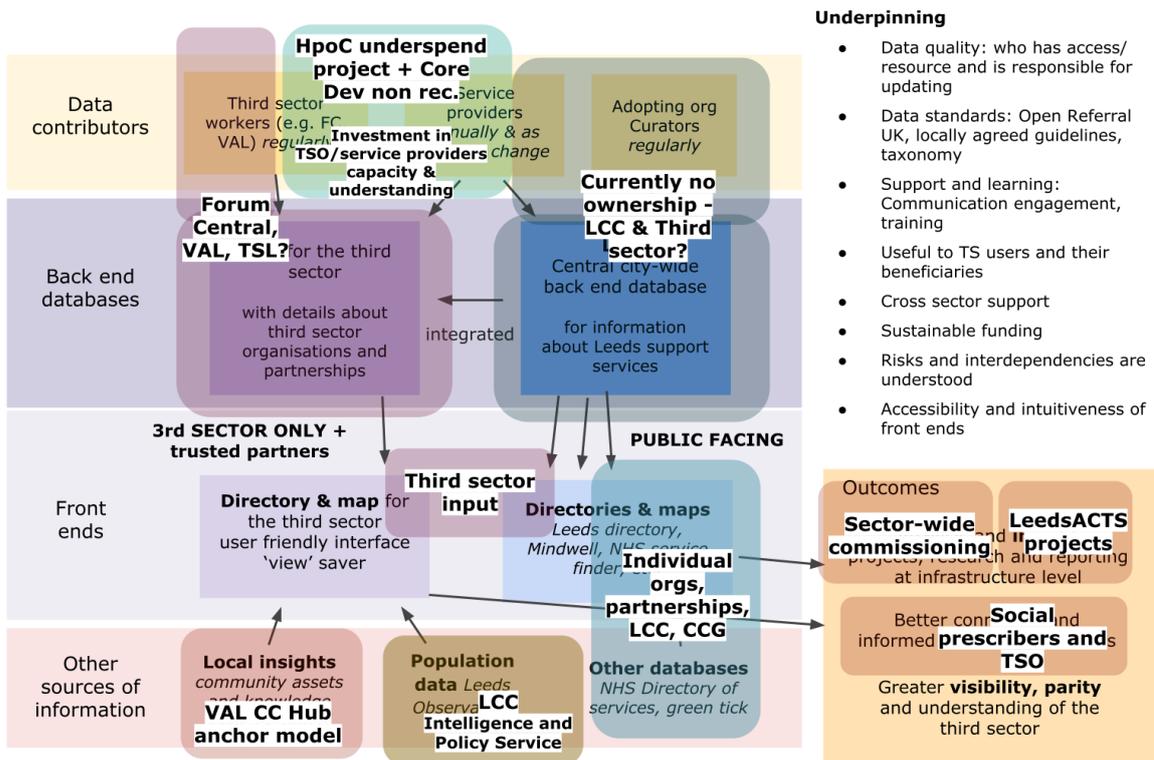
<https://www.england.nhs.uk/wp-content/uploads/2021/06/B0905-vcse-and-ics-partnerships.pdf> pp12-13

Appendix 4

Third sector data and mapping systems



Third sector data and mapping systems



Appendix 5

Extract from [HPoC Third Sector asset mapping scoping summary](#) (Nov 2021)

Underpinning requirements for LOOP/mapping success

The key underpinning requirements for success and sustainability of tool are:

- **Data quality:** Requires clarity (and contracted, funded obligations) on who has access and responsibility for updating and maintaining data.
- **Support and learning:** Comms, engagement, training and shared learning opportunities for adopting organisations to keep info up to date and ensure ongoing capacity and building good practice.
- **Adopt recognised data standards:** Using Open Referral UK, locally agreed guidelines (based on known place based good practice) and taxonomy. Avoiding duplication, building consistency.
- **Useful to TS users and their beneficiaries:** content must be TSOs themselves i.e. beyond a tool that helps those representing the sector to articulate its assets/strengths. This is critical for ultimate success of the tool if there is an expectation for TSOs to contribute to its development and maintenance.
- **Cross sector support:** from e.g. LCC and NHS and other partners with sustainable investment/funding of activity to support and match TS commitment.
- **Risks and interdependencies are understood:** Figure 1 below illustrates the critical factors and interdependencies that need to be considered whilst moving forward with the project.
- **Accessible and intuitive interfaces,** designed to be easy and simple to use with options to search against wide range of criteria depending on need.

Produced by Nifty Sustainability CIC for Forum Central December 2021, and building on their State of the Sector report

Appendix 6

Links to documents or extracts referenced

- [State of the Sector page on the Forum Central website - Report in full](#) by Nifty Sustainability and Leeds Beckett
- [Digital Enablement of the Third Sector in Leeds](#) in draft, by Karl Witty, not yet widely shared.
- [Third Sector Data and Mapping Systems diagram](#) in draft, by Jenny Bull, to articulate the thinking around two emerging databases, not for wide sharing.
- [HPoC \(Harnessing the Power of Communities\) underspend project - Third Sector asset mapping scoping summary](#) by Nifty Sustainability, as Phase 1 of the HPoC underspend project which aims to build capacity, shared understanding and alignment where possible of third sector asset mapping, which links into Loop and a third sector CRM.
- [Loop Critical Options v1.0 091221](#) by Jenny Bull, to aid next step decision making around Loop.
- [Loop interdependencies diagram 091221](#) by Jenny Bull, to illustrate what factors would influence the success of Loop.