



Liverpool City Region Civic Data Cooperative

Challenges of developing new models for civic data
stewardship for the Liverpool City Region

Our Purpose

Our vision

A cooperative, data-sharing platform that enables better health and care for people everywhere

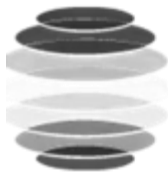
Our mission

Enabling positive change in health and wellbeing through data and cooperation



Building on momentum

- Liverpool City Region's World-leading response to the pandemic has created a strong, collaborative environment for improving care through better use of data.
- Projects like Connected Health Cities demonstrated need for regionally focused and participatory approaches



LIVERPOOL
CITY REGION
COMBINED AUTHORITY



UNIVERSITY OF
LIVERPOOL



Community-based SMART testing programme, 2020



"Blossoms At Sefton Park" - part of the 2021 Events Research Programme

If projects cannot demonstrate trust it can be difficult to progress even if the use of data and AI is legal and could offer wider benefits

'Techlash' at Sidewalk Labs could mean smart city rethink

Alex Ryan, head of the MaRS Solutions Lab and a consultant on Toronto Quayside project, said less tech reliance and more civic engagement could be the new way

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Health

Care.data: How did it go so wrong?

Nick Triggle
Health correspondent

Wants to Sell Your GP Medical Records

Here's How to Opt-Out

Phil Booth
19 May 2020

HealthAffairs

COVID-19

Topics

Journal

Forefront

Medical Algorithms Are Failing Communities Of Color

What is Depression? Message Us
Message A Crisis Counselor On WhatsApp
Text A Crisis Counselor Symptoms

A suicide hotline's use of data echoes Silicon Valley's privacy debates

The Crisis Text Line's AI-driven chat service has

people can protect their priv
patients' GP data will be shared

Data Stewardship Model Examples



1. **Data Trust** - Devolve governance of data to trusted third party with a defined set of purpose.
2. **Data Co-op** - Useful for Platform Co-ops to think about how they are managing and using their data, and data donorship
3. **Civic Data Co-op** - Scaling across civic data rights-holders to create a shared approach to using data and developing secure, privacy-preserving solutions. To be developed as a form of multi-stakeholder cooperative advocating for open, collaborative and cooperative approaches to data and algorithms.



Importance of Public Involvement

Recommendations from Understanding Patient Data Workshop following response to GDPR challenges

1. Make secure environments the default for data access
2. Improve meaningful transparency about access to data
3. Invest in communications and media to respond to people's concerns
4. Clearly explain people's choices
5. Put new public benefit guidance (led by the National Data Guardian's Office) into practice
6. Involve the public more in decisions about health data





Round 'Ere

What makes you well?

Building community-led wellbeing data hubs in Widnes UK

Team: Dr Emily Rempel, Emma Lord, Dr Gianfranco Polizzi and Professor Simeon Yates

“WIDNES HAS BEEN MIGHTY; WE'VE DONE GREAT THINGS.”

Aim and Objectives

Build a community designed and governed wellbeing data hub using participatory research

1. Understanding what wellbeing means in Widnes
2. Imagining better solutions with data
3. Exploring this through the eyes of people who live in Widnes



This project has been approved by the University of Liverpool Research Ethics Committee, approval number: 12124

What We Heard

- Hopeful community growth based in pride of the past
- A place where people are able to stay through all life stages
- Recognition in the role of agency in community opportunity and service provision



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What we did

The Round 'Ere Widnes Project ran for 12 months between November 2022 - September 2023, we split it into 6 phases:

1. PLANNING AND DESIGNING THE PROJECT (Nov 22 - Feb 23)
2. TRAINING AND ONGOING (June 23)
3. RECRUITMENT CAMPAIGN (March 23 - May 23)
4. COMMUNITY RESEARCH (July 23 - August 23)
5. DISTILLING THE INSIGHTS (Aug 23 - Sept 23)
6. CLOSING THE PROJECT (Sept 23)
7. USING THE INSIGHTS TO EXPLORE THE ROLE OF A DATA HUB IN WIDNES (Sept 23)



The Big AI Debate

Who Gets to Decide?



Supported by:

Funded by:

Questions from our communities



1. **How does AI work** in a clinical setting now in Liverpool?
2. How **can we democratise AI** when democracy feels broken?
3. Are the powerful **regulating themselves** and their use of AI?
4. **What kind of future** do we want from AI?
5. How are **biased datasets** impacting the way we use and understand outputs from AI?
6. How do we **create benefit for the Liverpool City Region** from AI that uses their data?



Hopes and Fears

“What hopes and fears (or questions) do you have about data and AI?”



Vision



To create a set of open principles on what trustworthy and beneficial data innovation looks like, deliberated and designed by residents. These will help inform future local projects that use data with an impact on people's lives.

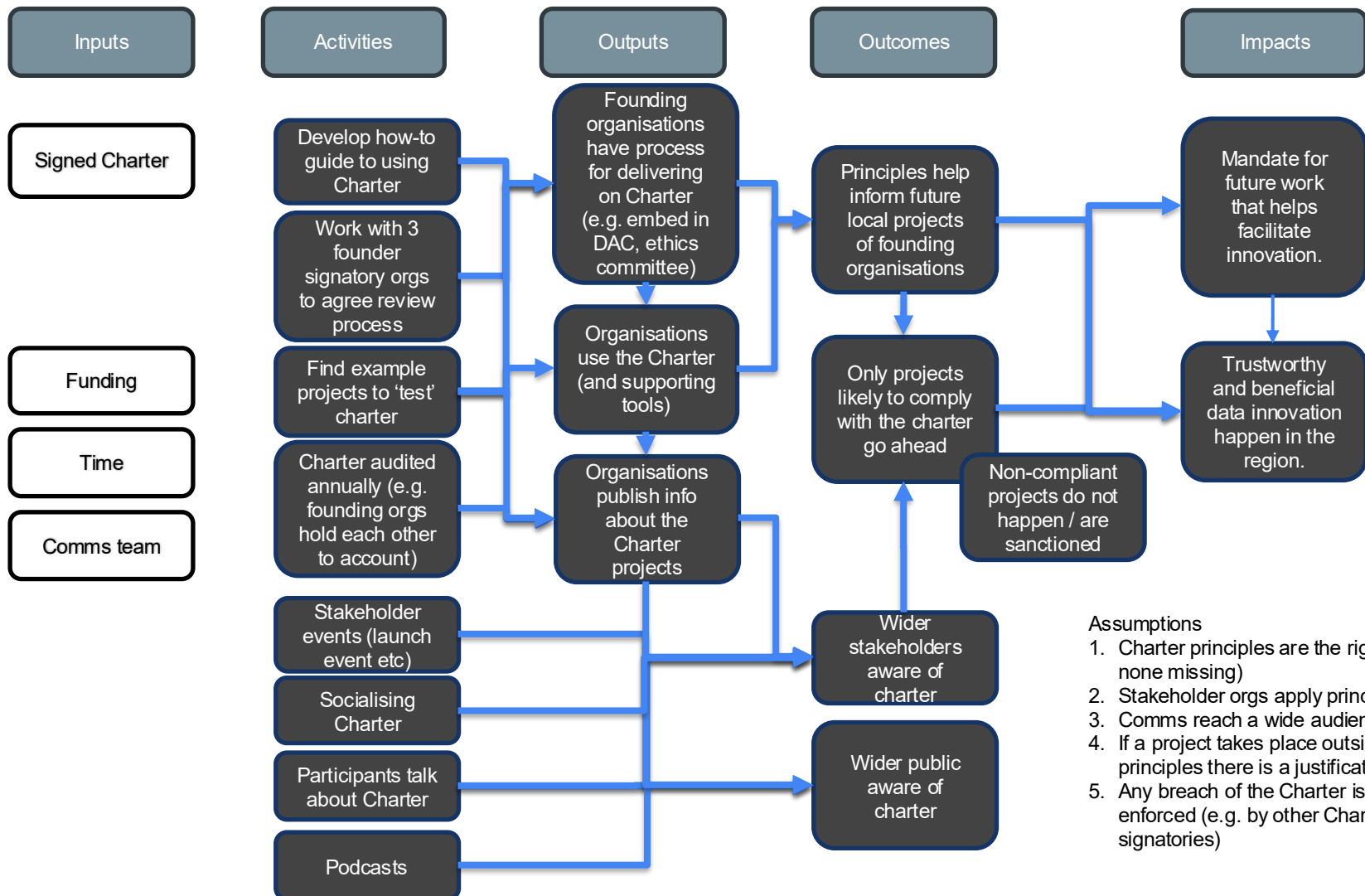




Liverpool Data and AI Charter

- #1 Beneficial
- #2 Security
- #3 Accountability
- #4 Transparency
- #5 Inclusivity
- #6 Privacy
- #7 Accountability
- #8 Trustworthy
- #9 Governance
- #10 Balanced Innovation
- #11 Oversight

<https://civicdatacooperative.com/residents-assembly/>



Assumptions

1. Charter principles are the right ones (and none missing)
2. Stakeholder orgs apply principles correctly
3. Comms reach a wide audience
4. If a project takes place outside Charter principles there is a justification why
5. Any breach of the Charter is clearly enforced (e.g. by other Charter signatories)



- Bringing together leading experts from academia, the NHS, local government, charities and industry
- Pioneering progressive civic data uses and responsible AI solutions with and for the residents of the Liverpool City Region
- Fuelling innovations for health, social and economic advancement



Thank you

www.civicdatacooperative.com

[@CivicDataCoop](https://twitter.com/CivicDataCoop)

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