

Health and Social Care Data Futures Report

LORIC / The Data Place 11 March 2019

An event to explore the use of data in the Health, Wellbeing and Social Care sectors through shared visions, key milestones and individual needs.

Improved
regulated
provision for
children &
young people

WITATA TW3V911
30

ACCESSING
CHILD CARE
CLASS 55-
AD 511

Emplo
5

Reach
Economics
Employment
Economic
Economic

Y2020/2021

2020/2021
Core
Order
Order

We gathered together
participants from local
government, academia,
and sector organisations.

Objectives

- Collaborating on shared visions for the sectors.
- Identifying steps and requirements to achieve the shared visions.
- Understanding what data is relevant.
- Identifying key organisations and individual.
- Locating where participants fit into the picture: where they can help; and what help they need.

Agenda on the Day

1. Introductions.
2. Visualising the preferred future of health, social care and wellbeing.
3. Working backwards on what needs to be in place to achieve the vision.
4. What data is required and available?
5. Identifying next steps.

Outputs

1. Visualised visions for health, social care and wellbeing futures.
2. A list of activities that need to happen.
3. New connections.
4. Immediate data challenges to work on.
5. An understanding of what help is needed.

Framing

We asked participants to think about what good health social care and wellbeing might look like in fifteen years' time.



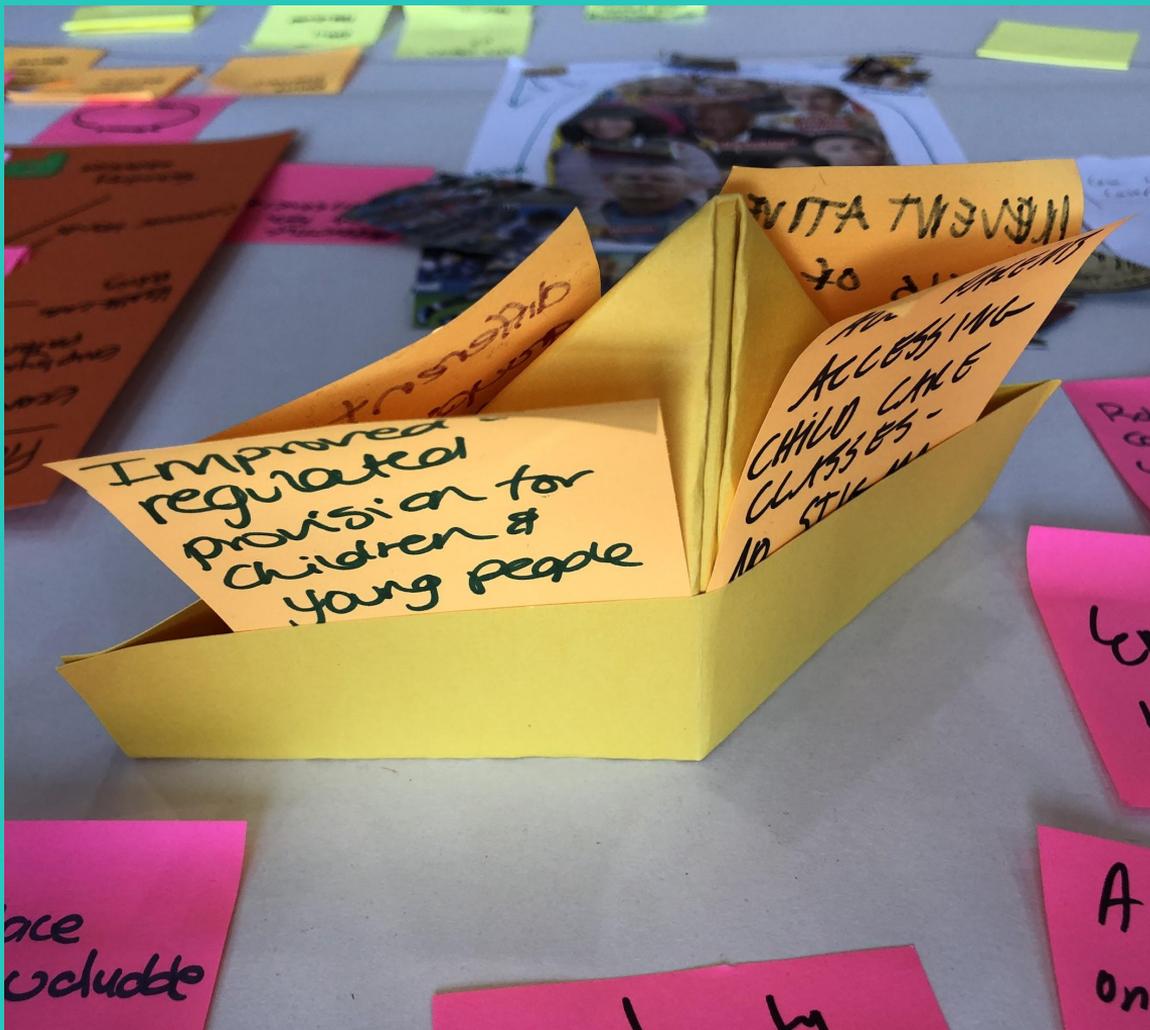
Joined-Up Services:

New ways of ensuring that services for people collaborate fully around the person's needs and agency rather than working in their own silos.



Infrastructure for People:

External infrastructure that helps health rather than making it worse.



Wellbeing as a collective responsibility:

The idea of a long-term culture change that makes it easier to live in society with a health or social care issue.

Young people and social media.

Better adjustment of younger people to the ever-increasing levels of interpersonal connectivity we are experiencing.

TOLD ME
ON INSTAGRAM
BUT WHEN
TO MUM
AND TEACHER
AND OTHER PEOPLE
I REALIZED
THAT INSTAGRAM
IS WHAT I MAKE
AND THOSE
AND I HAVE
TO SAY WHAT'S OK
AND I WHO IS NOT
SO BE NICE
OR BE BLOCKED



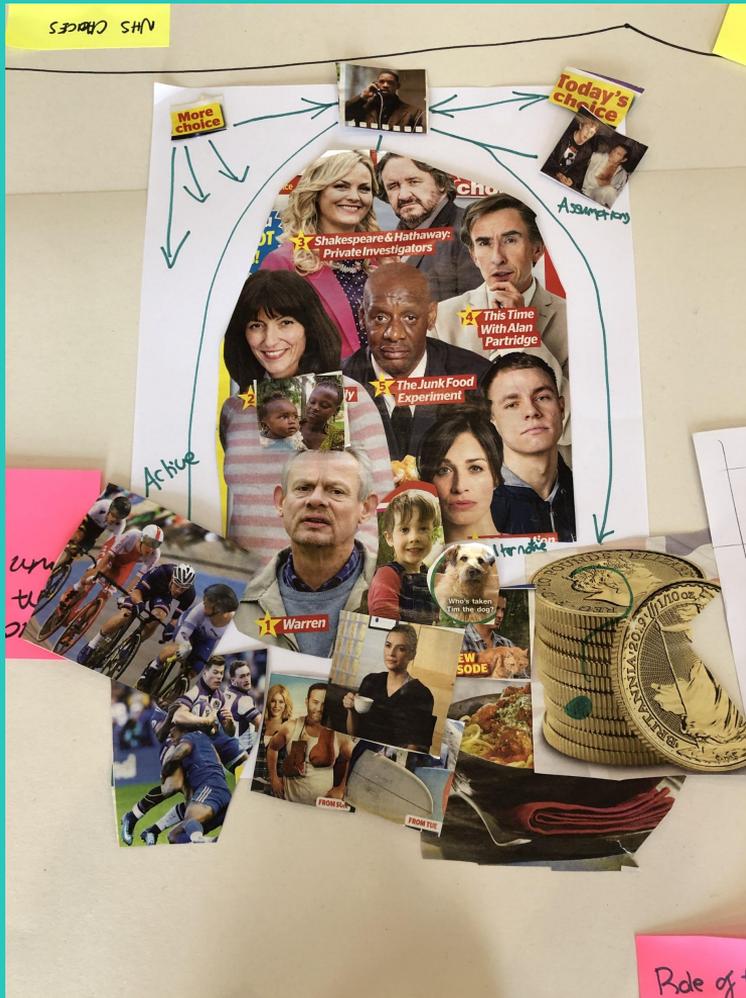
Better lives for older people:

More opportunities to get the most out of life and contribute as well as being more comfortable.



Engaging with nature:

A deeper, healthier
relationship with the
natural world.

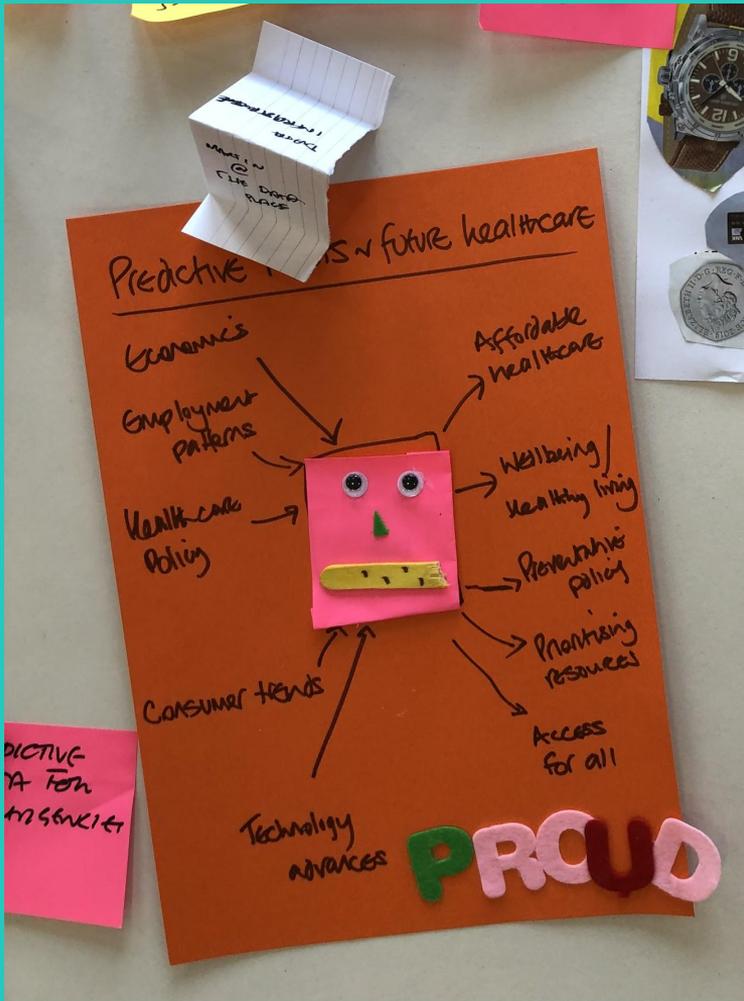


Better support for looking after ourselves:

Self-service options, better information, and a more mature overall culture of self-care.

Better use of data and technology:

A healthy relationship with technology that respects our privacy and acts ethically whilst giving us the help and support we need when we need it.

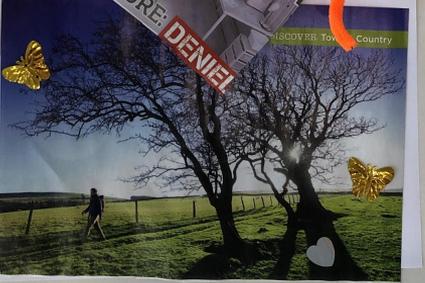




part and better health out ones

outdoor activities a part of everyday living

More Physical Activity Centres



natural habitats are accessible

focus on sources - Council - Tax collection - agricultural

THEY ARE...

Promoting healthier living:

Ways to influence behavior to avoid problems developing (and reduce demand on services).

Better diagnoses for Autism and ADHD:

Mental health issues to attract similar levels of profile and investment as physical health, including better diagnoses in children and adults.

UNDERSTANDING → SUPPORT

NOT ONE APPROACH FITS ALL

Town Mouse

Country Mouse

INDIVIDUALISED SUPPORT

A positive environment

We've come a long way



SERVICES THAT DON'T LABEL & STIGMATISE, BUILD ON THE STRENGTHS FOR INCLUSION



Hidden treasures

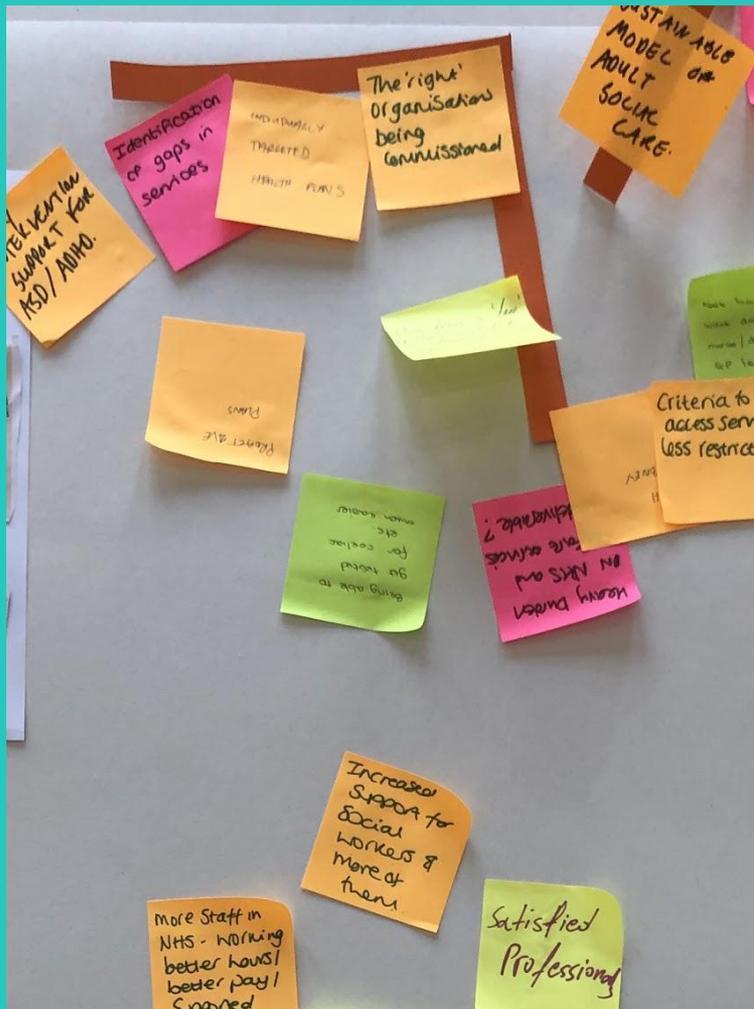
faster diagnostic pathways for ASD ADHD

Children and autism/ADHD
Parental support
Understandings.

EARLY INTERVENTION SUPPORT FOR ASD/ADHD.

ding of

open talk



Supporting organisations and professionals:

Those working in the sector to benefit from a mature support network, sustainable sources of funding, and new ways to make a difference.

Steps and Milestones

What are the prerequisites
for these futures to come
about?

Joined-up services

- Establishment of care networks
- Provision of carer/provider co-working spaces
- Evolution of #OneTeamGov to include user networks
- Better definition of Public health indicators
- Better understanding of the causes of homelessness
- Collation of consistent, standardised data by all services
- Sharing of standards for impact measurement

Joined-up services (continued)

- Development of an Impact measurement toolkit
- Enabling local groups to use standardised data
- Re-definition of needs and required provision
- Better funding of research and provision
- De-stigmatisation of sick people
- Better awareness of inherent privilege by sector participants
- A greater drive for equality across society

Infrastructure for people

- Investment in cycle paths separate from roadways
- Establishment of better rewards and incentives for cycling commuters
- A greater penetration of the use of food gardens in schools with school kitchens incentivised to use locally grown food.

Wellbeing as a collective responsibility

- Provision of antenatal classes for all parents
- Development of policies that promote wellbeing
- Acceptance of responsibility for wellbeing by organisations
- Design of systems to reward wellbeing, including employee wellbeing
- Provision of self-help systems for carers
- Awareness that there is always someone to call (like Childline)
- Development of systems to look after carers' wellbeing

Young people and social media

- Development of a culture that
 - rewards non-use of social media
 - Features less demonisation of teens (they need services too)
 - Provides more spaces for young people to socialise
 - Listens to young people's concerns
- Provision of health mentors to take people through a cycle of change
- Establishment of restorative approaches in schools
- Increase in the means for young people to organise
- Delivery of more outdoor/gym activities for teens

Better lives for older people

- Increased cohesion of the “team around the adult”
- Emergence of a culture of listening to what people need and not making assumptions
- Collaboration on joint solutions, (county/district councils, NHS, voluntary sector, private providers)
- Establishment of better support and help for carers to remain in employment
- Provision of more time-flexible services
- Development of structures to help people to work for longer

Engaging with nature

- Emergence of “Nature time” social prescribing by health professionals
- Recognition of the links between environment and health

Better support for looking after ourselves

- Provision of training, education and understanding about health and social issues earlier on in schools
- Development of “whole child” teaching including mental, financial, and physical dimensions
- Learning from other countries
- Education to have greater focus on life skills
- Design and delivery of step-up/step-down packages of care/service provision
- Development of curriculum and teacher training

Better use of data and technology

- Development of more comprehensive self-diagnosis tools and remedies
- Provision of more open data for self-diagnosis tools
- Development of “NHS Choices v2”
- Establishment of a European data lake
- Design of ethics frameworks for automation, AI, machine learning

Promoting healthier living

- Provision of monetary incentives to live healthier lives
- Startup of “Compassionate Lincoln” - a local branch of the global movement for compassion
- Delivery of a Social Responsibility Charter (Lincoln City Council)
- Policy development so that Council employees are more active in wellbeing policy and resources

Promoting healthier living (continued)

- Establishment of better Corporate Social Responsibility as a core business practise
- Development of business theory showing that compassion provides return on investment
- Promotion of skills for living in Schools

Better diagnoses for autism and ADHD

- Provision of diagnostic testing for all children and young people as standard
- Identification of support services that are needed while awaiting diagnoses.
- Design of services informed by those with lived experience
- Empowerment of teachers to work more flexibly with those with these conditions
- Provision of more funding for teaching

Better diagnoses for autism and ADHD (continued)

- Opening up time to talk in schools
- Rewarding personalised approaches and collaboration in education
- Provision of better training of professionals to help, including teaching staff
- Establishment of continuous improvement of the education system to evolve with societal changes

Better diagnoses for autism and ADHD (continued)

- Implementation of “specialist mainstream environments” in education
- Provision of early diagnosis for mental health issues
- Improvement of governance and professional oversight
- Development of a canonical library of mental health symptoms

Supporting organisations and professionals

- Development and dissemination of advocacy research, toolkits and better networks
- Improvement of advocacy arrangements to create a level playing field
- Development of better distance learning options for students, employed people and staff development

Data

From the future visions and required actions we developed a list of necessary and useful datasets and data types to explore.

- Social return on investment studies
- Short/long term impact of Corporate Social Responsibility programmes
- Outcomes for children linked to parents attending antenatal classes
- Data about whether being diagnosed with autism helped or hindered young people
- Statistics about mental health in young children
- Whole life and multi-generational data
- Information on how data how data collection will be used to feed forward into better practise
- Data on the effects of good teachers on pupils' quality of life?

- Information on the protocols, systems and data sharing agreements for sharing data to inform services
- Data on how symptoms impact on life, housing, employment, crime, health, etc
- Data on numbers of people with a diagnosis versus those awaiting a diagnosis
- Critical evaluation of data on diagnoses
- Data on available services and stakeholder types
- Data on age of diagnoses and demographics
- What interventions are working and what is missing in ADHD/autism treatment

- Information on standard data collection tools and toolkits
- How training is informed and created: who is doing what and whether it meets needs
- Data on those who don't make the waiting lists
- Students with mental health issues and disabilities
- The measured impact of early diagnosis on achievements and quality of life
- Outcomes data for long term conditions
- Economy and wellbeing data
- How having your needs met makes life worth living
- Impact data for each sector

- General demographic data
- Data on the effects of lack of diversity in specific sectors
- Collection of baseline information on needs (JSNA)
- Data from multiple organisations to evidence needs
- Data from service user consortium groups and boards
- Experience data from service users
- Statistics on preventable deaths
- Soft outcomes data
- Employment statistics, benefits and pensions data
- Data on outcomes with and without diagnoses

- Hospital and care homes admissions and death data
- Data on professionals experiencing mental health issues
- Data on ideas from parents and professionals about support
- Data to support employers standing up for their staff
- Impact on CIN, CP, LAC figures
- Data on the links between physical space and lack of social media usage
- Stats on loyalty and achievement at work

- Data on how young people socialise
- Data on weight and fitness for comparison
- Data on local green spaces (locations, accessibility, costs and opening times)
- Data on local food production, distribution costs and blocks, number of allotments
- Data on the costs of cycle path construction
- Data on the uptake and impact of cycle to work schemes

Data Recommendations

Baseline Datasets

The workshop identified a whole range of baseline datasets around the economy, local assets, health and wellbeing that would provide the basis for a clearer picture of how Lincolnshire is service its residents and how it compares to other parts of the UK.

Longitudinal Studies

It's clear that much of the useful data around health, social care and wellbeing needs to be gathered over longer periods of time to be able to understand impacts and trends. Finding datasets that go back more than ten years and planning to gather data over the longer term should be priorities. Examples include:

- Tracing the wellbeing effects of schemes that change environments eg new roads
- Intergenerational studies on dementia that track inherited versus developed aspects of the disease
- Life expectancy data over centuries compared to economic data

Qualitative Data

There's a definite need for better data that captures lived experiences, needs and qualitative research into impact in order to get a richer picture of the health, social care and wellbeing sectors.

Alongside this is the need for better tools to help process and visualise qualitative data.

Impact Evidence

Much of what is needed for future planning and funding in these sectors is dependent on solid evidence of impact.

Strengthening existing toolkits for impact measurement and helping organisations standardise will enable better comparison of different interventions and delivery models.

Data Policies and Protocols

Many of the workshop participants pointed to the need for better collaboration between organisations and better ways to ensure that the right data can be shared in order to accelerate positive impact.

This means strengthening data protection capabilities in organisations at practitioner level so that sharing carries less risk and can be handled with less internal bureaucracy.

Combined Datasets

Finding creative ways to combine datasets (such as green spaces and mental health) could provide stronger evidence bases and opportunities to innovate.

This means tools to help - like open data platforms - but also events that bring out the creativity of participants, structured or otherwise.

Comparative Data

Ways of comparing impacts of interventions and non-interventions would provide a better picture of what actually works in the health, social care and wellbeing sectors.

Next Steps

What should we do next?

- Data gathering
- Targeted events
- Working groups

Data Gathering

- Items from “Data” section of this report to be collected and published on the portal where possible
- “Hit list” created of desirable datasets we don’t yet have
- Planned programme of stakeholder engagement to get the data on the hit list

Targeted events

- Qualitative data workshop
- Structured games for combinatorial creativity (eg Datopolis)
- Specific workshops to bring data owners from different domains together into the same space
- Impact measurement workshop

Working groups

- Comparative data working group
- Sector data sharing group
- Impact measurement working group

Link to stitched photo of
the final workshop
material.

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