Adolescent Health Study (AHS): a step change for adolescence research

Spring 2022 programme of events: summary of discussions

AHS: a UKRI Infrastructure Fund Project

The Adolescent Health Study (AHS) is part of a portfolio of investment by UKRI in the UK's research and innovation infrastructure[1]. The study will follow over 100,000 adolescents (eight to 18 years of age), gathering data about their health and lifestyle for a minimum of 10 years. It will provide unparalleled biological and real-time lifestyle data during a key life period of rapid mental and physical development and explore the health of adolescents in the 2020s and a post-COVID-19 world.

Investment in this national study will generate a resource for researchers, policy makers and other stakeholders to understand critical health and wellbeing trajectories that have their roots in late childhood or adolescence. The AHS platform will provide an extensive evidence base on which to develop interventions and policies to improve population health

£62 million from the Infrastructure Fund has been allocated to the MRC (Medical Research Council) for the study, subject to business case approvals. [2]

AHS: Virtual Programme

A range of stakeholders (including young people and parents) have input into the concept, design, and feasibility of AHS from conception through to recommendation for funding by the UKRI Infrastructure committee. This development programme has continued with the purpose of giving AHS a strong start, with three virtual events hosted in Spring 2022 to introduce the study to the wider community and progress its design through discussion of the potential challenges and opportunities. The MRC expects to launch a funding call for methods development in September 2022, in preparation for the main study which is anticipated to start in 2024.

The objectives for the virtual programme were to:

1. introduce and update the community on the vision of a UK adolescent health study and its core design features

2. understand ways to optimise the recruitment and retention of study participants at different ages, including
   - generating ideas on how to overcome barriers and utilise enablers
   - examine how barriers and enablers may differ depending on the background of the participant (SES, ethnicity, gender, age, education, location etc)

3. consider which tools and assessments in studies with young people would add value to AHS
   - where have current tools and assessments been used successfully and where could improvements be made, geared towards AHS?
   - where are new methodologies/tools needed (example areas: dietary assessment, cognitive development, measurement of puberty)

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[1] https://www.ukri.org/what-we-offer/creating-world-class-research-and-innovation-infrastructure/funded-infrastructure-projects/

- which tools are suitable for which age ranges within AHS (where ages scoped range from 8-28)?
4. network to share experience and develop ideas in a non-competitive environment.

The programme kicked off with a 1-hour webinar, delivered by Professor Nick Wareham, MRC Epidemiology Unit and Chair of the MRC Population Health Sciences Group, introducing the vision for AHS on 21st April 2022. The session was recorded and is available to view: https://youtu.be/lamBBTX4jwE. A FAQ document was also produced and will be available to view soon.

This was followed by two 2-hour virtual workshops to share insights and expertise and develop ideas on key topics.

The first workshop held on the 11th May 2022 focused on the **Engagement of adolescents in socioeconomic and health research**. "*Examine the enablers and barriers to engagement with adolescents in research, identify if and how enablers and barriers differ between participants, determine what new approaches and methods are required to optimise recruitment and retention of participants in the planned study and consider how to develop and evaluate these approaches.*"

Whereas the second held on the 17th May 2022 focused on **Developing age-sensitive tools and assessments for studying the health and wellbeing of young people**. "*Discuss what tools and assessments exist already, examine how and when they are useful and where improvements are required, determine what new tools and methods might be required for use in AHS and advise on how to develop and evaluate these approaches.*"

This report summarises the main discussions from each of these workshops. An illustrator was present at both workshops capturing of discussions in a visual format, the images produced may be found at the end of this document.

Workshop 1: engagement of adolescents in socioeconomic and health research.

Professor Nick Wareham provided a quick over on the vision for AHS and the objectives for the session before attendees were split into breakout rooms and asked to consider and discuss s: enablers and barriers for engagement with adolescents in research, including the role of schools and parents; what diversity is critical for the study and what do we need to consider to ensure groups currently underrepresented in research are involved; what the existing approaches and engagement methods are and what improvements and new approaches are needed.

Workshop 1: enablers and barriers for engagement with adolescents in research, including the role of schools and parents.

Why would young people get involved and stay involved in the study? And what would stop them?

Work undertaken during the initial scoping for AHS highlighted that recruitment and retention of young people within a research study is challenging but young people will readily engage with research under certain conditions. Critical criteria for getting involved included:

- the research is of interest and relevance
- messaging regarding the study is clear and concise
- appropriate incentives are provided
- the expected commitment is clear

- methods for recruitment are age appropriate

Additionally, it was noted that young people tend to remain in studies with strong engagement strategies. Critical criteria for keeping young people involved included:

- establishing trusting relationships between the young people and the research team
- participation in the study including a social element
- clarity on what they will get from the study and how it will benefit their age group
- alignment of the study with their educational needs

At the workshop many of the discussions aligned with these findings and additionally highlighted:

- Young people would get involved and stay involved in a study where:

  o the impact and outputs of the study are communicated from the outset

  o they have ownership of the study, feel valued, feed into the design of the study and advise throughout, and the results of the study are shared

  o they trust the research team, a critical point in gaining this is ensuring that young people can build an understanding of what the research aims to achieve and seeing representation within the research team

  o it is clear what being in the study involves, with young person advisory group assisting the research team on how best to communicate and work with young people

  o they are rewarded for their time

  o participation is easy and enjoyable, fitting in with education and with a social element. This would require tailoring research methods to young people for example online questionnaires split into smaller parts that do not need to be completed in a single session, use of Apps for recruitment and gamification of surveys[3].

- Barriers to participation and reasons for leaving a study included:

  o not knowing why data is being collected and/or how it relates to them. It was highlighted that as the study is taking place over 10yrs that the importance to an individual could diminish over time or be altered by life changes for example moving and leaving school or leaving home.

  o fear of being judged, peer pressure and misalignment of the study with community values

  o concerns about privacy and the use of data/samples

- Approaches need to be agile and flexible, particularly with digital methods which are likely to rapidly alter over the study period.

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[3] Although digital methods were listed as examples it was noted that research teams would need to carefully consider those excluded by the use of digital technology

Virtual programme summary

- Research teams should not attribute failures to engage to lack of effort or any kind of deficiency from the participant but should look at failures or limitations of the system/approaches selected.

As study recruitment is set to take place within schools, what would get them involved and stay involved in the study?

Work undertaken during the initial scoping for AHS highlighted the critical need to work in partnership with schools utilising a mutual benefit model. Workshop discussants strongly agreed that the role of schools as a gatekeeper to participation was critical and highlighted the following:

- schools and teachers must be involved in the study, we also need to think about how to work with Local Government Associations, The Department for Education, CEOs (Chief Executive Officer) of academy trusts, social workers, and other community partners

- participation needs to be as easy as possible and provide value. It cannot interfere with school's daily business and must relate to the curriculum and support education

- incentives for schools should reflect their needs

- creating a sense of belonging can enable participation, therefore the study should look to work with schools within local areas and to facilitate partnerships

- persuading schools to participate in studies during the pandemic was harder due to the increased workloads of teachers and support staff and increased demand for their participation in research. These difficulties have persisted post-pandemic with additional burdens due to staff absences and well-being issues

- digital technology provision within schools varies, funding may need to be provided for purchasing equipment for use in schools and its set-up and maintenance

- the national pupil database is a rich source of central administrative data into which the study could link

Parents and guardians should be included in the decision to participate wherever possible and always if the young person is not yet competent. What do we need to consider concerning their role in the study?

Workshop discussions also identified parents, as a gatekeeper to participation but acknowledged that their role would alter depending on the age of the young person on enrolling in the study and as they age within the study and highlighted the following:

- there is a tricky balance between young people's privacy and the involvement of parents/guardians

- the research team must be visible to the parents, transparent about the study and ensure parental support for the study

- parents should feel valued in the study

Workshop 1: what diversity is critical for AHS and what do we need to consider ensuring groups currently underrepresented in research are involved?

Work undertaken during the initial scoping for AHS recognised that the study could not be representative of the UK population but instead should be sufficiently powered to effectively inform on policy interventions including data for understudied population sub-groups, utilising oversampling for those currently underrepresented in research. Workshop discussions supported this and highlighted:

- that understanding diversity is critical for studying physiological, genetic, and social determinants of health

- core diversity indicators included place, race and ethnicity, sex, gender and sexual orientation, age, socioeconomic status, religion, vulnerable groups and those with additional needs, and sexual orientation (specific comments and considerations are outlined in Table 1)

- that the composition of those who create, design, and undertake the study (e.g., research team, young people advisory groups etc) should reflect the range of people we want to work with in the study

- a need to train researchers to work with different groups using flexible methods for adaptation for working with young people with different needs

- the need for differential incentives for different groups

- the need for community advocates/champions
  - in co-designing the study
  - for framing the aims/objectives of the study in a way that their community can best understand
  - to build trusting relationships

Table 1: Core diversity indicators with comments and considerations highlighted at AHS Workshop 1

Diversity concept	Comments and considerations
Place	*studies to date tend to be urban-orientated, there is a need to include those within rural, and coastal locations.
Race and ethnicity	*use over-sampling to ensure minority groups are represented
Sex, gender, and sexual orientation	*females are more likely to participate in research than males *inclusion of young people identifying as transgender and non-binary and considering that administrative data may not accurately reflect their gender
Age	*what is important to someone when starting within the study will change as they become older *study design and methods will need to alter across the age span (youngest, aged 8 and oldest aged 28)
Socioeconomic status	*interweaves with other concepts e.g., place, ethnicity etc

	*as the study will work through schools is there a need to target schools within deprived areas to ensure those within lower-income groups can engage in the study?
Religion	*an underestimated determinant of health
Vulnerable groups and those with additional needs	*how the role of schools, parents/guardians etc would differ for young people in care, pupil referral units and those with special educational needs or disability *for those with special educational needs or disabilities the parent/guardian/school may play a more active role as a gatekeeper/facilitator

Workshop 2: developing age-sensitive tools and assessments for studying the health and wellbeing of young people

Professor Nick Wareham provided a quick overview of the vision for AHS and the objectives for the session before attendees were split into themed breakout rooms and asked to consider and discuss, over two rounds, the tools/assessments that currently exist and what new methods and/or tools might be required.

The themes were mental health, physical health, diet and nutrition, puberty and reproductive health, behavioural research, cognition and learning assessment, social determinants, vulnerable young people and those with additional needs, and wellbeing.

Workshop 2: cross-cutting themes

Across the themed breakout rooms several common discussion points arose which are summarised here.

Use of digital tools, wearables, and trackers

Most breakout groups discussed data collection using digital tools, wearables, and trackers. Examples included:

- actigraphy/smartwatches to collect data on physical activity, heart rhythm, rate and activity, blood oxygen saturation, and sleep
- smartphone cameras for completing photo diaries or recording facial expressions whilst surveys are completed
- apps to collect consent, deliver surveys and questionnaires and send notifications of a new task to complete
- virtual-reality tasks
- digital and location tracking
- in-ear EEG to measure brain activity

Advantages of using these tools included lower burden on young people (reducing attrition), these tools are less prone to response/recall bias and are more acceptable, interesting, and inclusive to young people than traditional in-person and paper-based exercises.

A critical concern was the feasibility and acceptability of accessing data from phones and wearables used by young people. There are ethical, data protection and privacy issues with digital and location and tracking. It was highlighted that it would be useful to explore what young people would and would not be willing to share and under what conditions.

Other concerns included accessibility issues for some groups (e.g., those in the younger age group are unlikely to have a smartphone and parents may not wish them to have one) and difficulties in developing/adapting/validating these technologies within the period of the study.

The burden of sample and data collection on young people

Most breakout groups discussed how much time young people would be willing to spend providing information and samples. This was discussed concerning individual tasks, the cumulation of tasks within the study and how all questions/measurements within the study would interact.

It was noted that passive data collection through digital tracking/wearables and data linkage could reduce the burden of assessment, however active data collection would be required and, in some cases, be preferred by young people. The groups considered that it would be essential for young people to be involved in determining the balance between passive and active data collection and volume/frequency of data/sample collection.

Creative, unusual, adaptable, and multi-disciplinary approaches

There was discussion in most groups and within the first workshop about future-proofing the study. This could include updating tools, methods, and questions over time, building in adaptability from the start to ensure the study reflects age-related, environmental and/or contextual change. This futureproofing should take place by working with young people and other stakeholders including industry.

Additionally, it was noted that technology will change over the next 10 years and data/samples currently inaccessible could become collectable mid-way through the study and we should have the flexibility to be able to include these as they arise. However, the research team would need to be pragmatic about updating tools, considering the need to use original tools/methods where repeat measures or links to existing datasets are required, even if that tool/method is no longer the best available. A combination of original and new tools/methods could provide a balance.

A further point of discussion was the importance of supporting unusual and creative collaborations to facilitate the development and evolution of methods, tools and measures and bringing in experts in areas not always considered. Examples included:

- legal advisors to consult on the type/among of data that can be collected, in particular where laws differ between the four nations

- ethical experts to advise and agree on approaches, particularly on consent models and digital data privacy/tracking

- technologists and software developers to advise on and lead the development of digital tools and technologies

- data management experts to consult on how data is collected, stored, and managed

- IT (Information Technology) support to advise and provide practical support to the research teams, schools and young people using digital tools and methods

Consent

How consent would be managed, and the role of parents/guardians and schools was a common topic. It was noted that young people must be involved in the decisions to participate and provide

assent/consent with age-appropriate information provided for informed decision-making. Parents/guardians should be involved in decisions to participate wherever possible and always if the child is not yet competent. The following points were raised:

- whether parental/guardian consent could impact the study findings. For example, would the study be biased towards parents/guardians who are keen for their children to be involved?

- schools will want to engage with parents on consent for the study

- innovative approaches could help or hinder consent processes, for example, making providing/withdrawing consent easier, or making the provision of consent off-putting if the approach is too innovative, inaccessible or risks data privacy

- the balance between the autonomy of the young person versus the involvement of parents in consent and the study. It could be possible to employ a sliding scale of who consents for who and when. It was highlighted that parental/guardian information is also incredibly rich and important, therefore there is a place for parental involvement throughout the lifetime of the study but the boundaries on what they report on would need to be clear.

Diversity

Like discussions at workshop 1, diversity and inclusivity matters were raised. It was considered essential to have diverse representation inform development and testing to ensure that tools are acceptable and informative across all groups. Points of discussion included designing tools/methods with the most vulnerable groups in mind and how best to adapt/tailor tools/methods so that they are acceptable and appropriate for all groups.

Workshop 2: theme specific discussions

Theme-specific discussions are summarised in Table 2, comments and considerations have been grouped under the following headings: existing tools/measures, requirements/challenges, and new tools/measures.

Table 2: Theme-specific comments and considerations from Workshop 2

Theme	Comments and considerations
Behavioural research	Existing tools/measures: online virtual-reality behaviour tasks, strengths and difficulties questionnaires, Confidence-Based Learning (CBL), CANTAB battery, exercise/sleep tracking, teacher/parental/guardian reporting

Requirements/challenges: having a tool that is consistent and validated across the full age range, ethical considerations on passive data collection and consent

New tools/measures: Max Plank designed body visualiser (health avatar) could be adapted to add in measures of puberty, sense of self/perception and link to behaviour, health, diet, and exercise. |
| Cognition and learning assessment | Existing tools/measures:
*wearables/digital devices for monitoring physical activity, sleep patterns, social media usage etc
* ecological momentary assessment via mood question notifications on phones |

	*technology available to measure impulses via the skull but this is not portable and is far off in development, even in labs its 3hrs sitting and the data quality is poor *survey questions; good and validated tool but with limitations Requirements/challenges: *cognitive tests tend to take place in a clinical setting. Some have been done online with adults but only in small numbers, with uncertainty as to how this would translate to young people *learn from other studies e.g., health behaviour in school-aged children study *comparable measures across age ranges, neurodiversity etc New tools/measures: *evolution of tools to obtain consent and provide information to young people and parents *improvements to in-ear EEGs and/or development of new wearable devices
Diet and nutrition	Existing tools/measures: food diaries/dietary recall (e.g., Intake 24 https://intake24.co.uk/), biological sampling (blood for fatty acid intake, hair for fish intake, veganism, drug/alcohol usage, urine analysis), photo diaries, continuous glucose monitoring Requirements/challenges: *burden on participants logging food intake over extended periods. When recording food for more than 2- 3 days there is a substantial drop-off in participation * young people should help determine the methods and what is measured, the best method could differ depending on the location of the study *training and/or photo evidence is required to assess portion sizes *self-reporting makes data easy to obtain but has limitations i) response/recall bias and ii) fabrication of results to give the right impression by both the young person and parents (or influenced by parents) *recruiting young people into studies with an exercise component can be challenging *sensitivities around weight/BMI, body image and disordered eating New tools/measures: *currently a gap in linking socioeconomic factors to diet. Diet and the environment that people are making their dietary decisions in, has yet to be fully investigated in this age group *GPS data to see the location of food intake at home vs. school vs. restaurant etc. Noted that this is feasible to collect but has ethical and data privacy challenges *examining the school food environment instead/as well as at the individual level *develop activity monitors to detect eating episodes and link them into food diaries/dietary recall assessments *new dietary biomarkers
Mental health	Existing tools/measures:

	*passive sensing of social activity (e.g., audio-sampling) and social network activity (limitations based on ethical and data privacy concerns) *clinical depression measures, broader wellbeing measures not as well defined/validated *traditional questionnaires (GAD PHQ etc) and teacher and parent/guardian assessment *ecological momentary assessments Requirements/challenges: *quantitative measures are poor at capturing the experience, need to utilise qualitative measures (structured, standardised interviews) *language needs to be accessible to all and the research team needs to understand the ways in which young people speak about their relationships *capture the interrelationships between physical measures and mental health e.g., sleep and physical activity *dissecting out mental health conditions; anxiety, depression, bipolar, OCD (obsessive compulsive disorder), psychosis etc *feed data back to schools (at a school level, not individual) so that they can make timely changes *ethics and safeguarding New tools/measures: *improve sleep and activity assessments *photo-voice to capture daily life, incorporating free-text qualitative assessments with the pictures, has been done with young people in smaller sample sizes *better mobile EEG equipment *gamification of digital assessments
Physical health and biological samples	Existing tools/measures: saliva collection (least intrusive but not suitable for all measures), dried blood spots (good for optimising storage and less intrusive than venous blood but does it provide enough information), urine and stool samples, hair samples (for retrospective hormone analysis), body composition (height, weight, waist circumference, arm pinch, grip strength etc), wearables measures (heart rate, sleep etc), data linkage (e.g., CPRD (Clinical Practice Research Datalink)) Requirements/challenges: *a centrally organised analysis centre, with a common central lab to enable result comparison and reduce analysis variability *standardisation across testing centres (standardisation for analytical samples is critically important) *annual reporting on body composition *collection of bodily fluids will not be possible across the full cohort; the study should be designed for a subset from the outset New tools/measures: *home sampling is more acceptable now; we should focus effort on looking at innovative ways to make home sampling reliable and free from manipulation *utilising video/photo confirmation and/or virtual consultation for body composition measures

Puberty, sexual health, and relationships	Existing tools/measures: *currently a lack of short self-reported measures on healthy intimate relationships in young people *hormonally influenced physiological events such as menstrual cycle and circadian rhythms are currently hard to measure over time *events-based analysis is useful. E.g., for sexual risk behaviour, an event is a sexual encounter (complete diary entry, unit = one event). The nature of events will alter with age Requirements/challenges: *difficult to talk to young people about sexual behaviour and some communities are less ready to discuss it than others, we need carefully considered and constructed questions for more sensitive topics *how to standardise questions that are appropriate across the full age range *consider the role of digital tools/content and pornography in relationships *ethics and safeguarding New tools/measures: *adapting existing questions on puberty for young people that identify as transgender or non-binary *leveraging a psychosocial approach (instead/as well as a biological/medical approach) - talking vs. just measuring or labelling
Social determinants	Existing tools/measures: *link to existing/routine data: educational attainment, data on the local area, public transport provision, urban vs. rural, diversity, free school meals etc *questions on educational experience, peer and family relationships, socioeconomic status, family affluence scale (has been validated in young people, asks questions on own bedroom, family holidays, dishwasher in house, number of bathrooms etc) *online vs. traditional questionnaires Requirements/challenges: *need to consider a range of different social contexts, including schools, family life, peer relationships, neighbourhoods, political aspects of the neighbourhood, digital/online world, community, religion, young people's identity, leisure time etc *the role of parents in answering some of the questions, especially those in the younger age bracket *not a single template, measures need to be responsive and flexible *social media use changes with age, if this is being used as a tool it must be coproduced with young people *need to keep standard measures but semi-structured interviews may not be feasible at this scale New tools/measures: *cultural probes, i.e., send individuals a camera and they photograph items around the house *record and analyse information using advanced data sciences e.g., AI (Artificial Intelligence) to interpret categories of behaviours

	*work with people not in our community to develop new methods/tools. E.g., people behind social media platforms study and recognise social interactions/activity differently *use of GPS/Bluetooth mapping to understand how people in different settings spend their time (ethical and data privacy concerns)
Vulnerable young people and those with additional needs	Existing tools/measures: *currently a gap in appropriate measures for assessing mental health for young people with reading, writing and language difficulties *learn from existing studies and cohorts Requirements/challenges: *build strong trusting relationships to recruit and retain these young people in the study (with young people, PRU and SEND provision, youth justice system etc) *consider benefits of participation for the individuals, be realistic and consider potential harms *strong co-production to determine what measures are appropriate *capture the influences of peers e.g., drink and drug usage, sexual behaviour, self-harm, truancy, gambling *capture the interrelation between different health behaviours New tools/measures: *health economics based on quality-of-life measures built on qualitative studies in young people, rather than adapting adult measures *evolve ecological momentary assessments *current family functioning measures are focused on parents; could design new measure to collect thoughts of young people on family functioning *food security measures; currently look at the household, but young people's understanding may be different. An individual young person could be food insecure within a food secure household. Could look at the money available to the young person (e.g., pocket money) separate from parental income
Wellbeing	Existing tools/measures: * Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS), a 14-item questionnaire covering both psychological functioning and subjective wellbeing facets of mental wellbeing *Rosenberg's Self-Esteem Scale *PHE measuring mental health and wellbeing in young people, questions include "How satisfactory is your life?" *ONS has proposed a set of children's wellbeing measures grouped into seven domains *quality of life measures *for mental health measures, Wellcome/NIMH have mandated common measures that all studies should use Requirements/challenges: *currently we do not fully understand what we mean by wellbeing or how to measure it. Sally Davies was quoted as saying that *the concept of mental wellbeing is not well-defined, its measurement is imprecise and this "crucially compromises the credibility of the evidence base."*

|	*common validated measures that work across age groups and capture change
	New tools/measures: *use digital technology to relate broader aspects such as exercise, activities, and screen time to mental health and wellbeing *the link between technology use/gaming and mental health/wellbeing, leveraging passive tracking of screen time usage (an issue is as technology changes questions can become irrelevant) *evolve existing digital technology/Apps to collect the data you want

Acknowledgments

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Workshop 1: Image by Sally Pring, Live Illustration Ltd

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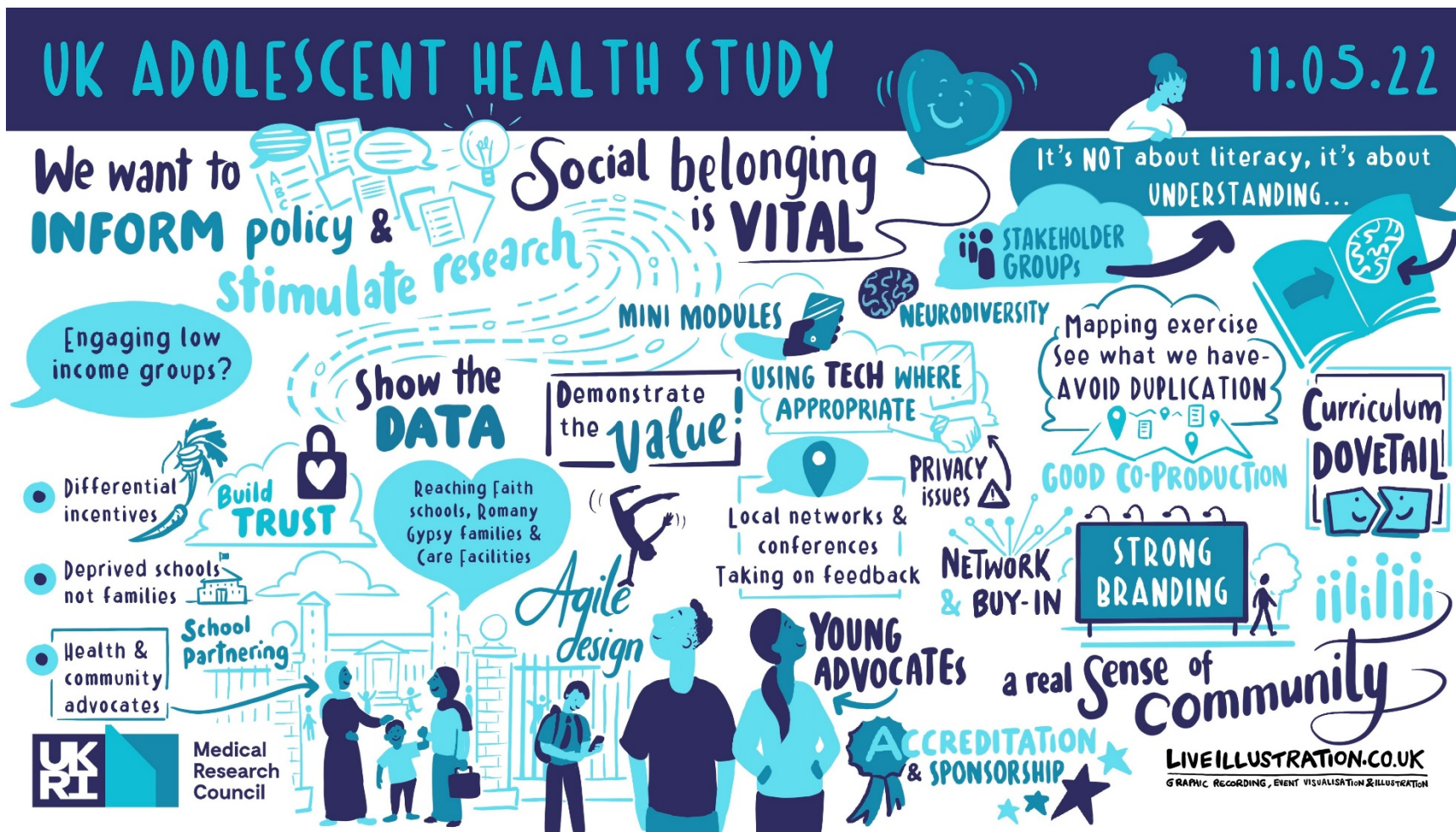
Workshop 2: Image by Sally Pring, Live Illustration Ltd

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