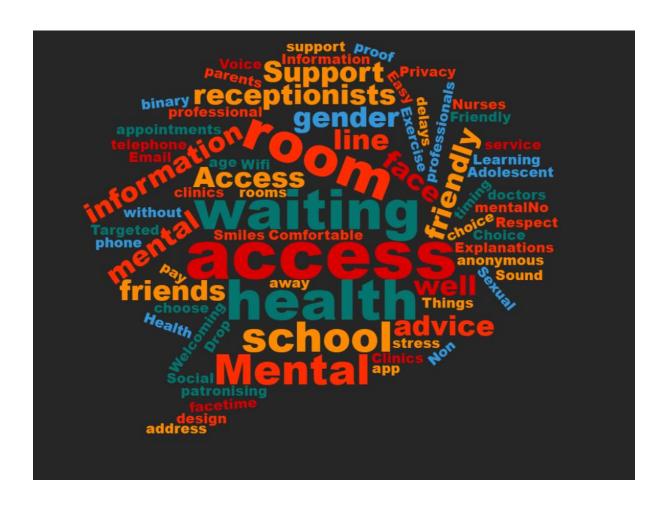
"What does it mean to be an adolescent in the 21st century: implications for health and healthcare"

A one-day workshop across specialities

17 October 2017



#### Introduction

Adolescence is a time of transition and growth – physically, cognitively and emotionally. Concepts of self, attitudes to risk, susceptibility to peer influence<sup>1</sup>, and ability to understand other's perspectives all undergo major changes. Many health problems present specific challenges in this age group, including those that may first present in adolescence such as sexual health needs or mental health problems. For example, it is estimated that half of all lifetime psychiatric disorders start by age 14 and 75% by age 24<sup>2</sup>. Furthermore, clinical management of both physical and mental health problems may need to evolve alongside the development and priorities of the teenager such as in diabetes or eczema<sup>3</sup>. Adolescence is also a time when behaviours that influence health throughout ones' life may be first experienced or established (for example smoking and eating patterns)<sup>2</sup>.

In the UK, there are 11.7 million young people aged 10-24, representing one fifth of the UK population<sup>2</sup>. Adolescence and young adulthood have been overlooked in considerations of global health and social policies until recently<sup>4</sup>. It has been observed that the specific needs of young people are often neglected by both primary and secondary care, with a general belief that adolescents are on the whole a healthy group who rarely present to their GP<sup>5</sup>.

Recent data shows that young people are, however, regular users of healthcare, particularly primary care and community contraception but also Children and Adolescent Mental Health Services (CAMHS), hospitals and Accident and Emergency (A & E) departments. Although many are satisfied with their experiences, others are not, and the proportions who are 'not' tend to be higher than for other age groups. For example, a recent survey in the UK found that although on average young women aged 15-19 visit their GP 4.5 times per year, one fifth of them felt uneasy with their GP at their most recent visit<sup>2</sup>.

The World Health Organisation has set global standards for quality health care services for adolescents. Their health rights include care that is considerate, respectful of privacy, emphasises the importance of confidentiality, and the participation of adolescents in their care decisions<sup>6</sup>.

Clinicians may find consulting with adolescents challenging, and developing the resources and skills of health care professionals is important<sup>7</sup>. Adolescents are neither 'large children' nor 'small adults', and services and professionals need to be developed to meet the needs of this large sector of the population with significant unmet needs. The lack of training to manage the needs of young adults has been identified as a significant barrier to delivering good adolescent care<sup>8</sup>. Dedicated adolescent units improve outcomes, but a survey of Royal College of Physician members found that only 16% of respondents had access to these<sup>8</sup>.

As children with long-term conditions grow through childhood to adolescence and then adulthood, attention needs to be given to the transitions of their care between services<sup>9</sup>. A UK review found that experiences of transition were highly variable, with good practice guidance not always followed, although there were also cases of excellence, and made recommendations to support transition, including good planning<sup>10</sup>. The first UK cohort study systematically looking at the transition process from child and adolescent to adult mental health services found that one third of young people were not referred on to adult services, one fifth of those referred were never seen by adult services, and only 4% experienced ideal transition<sup>11</sup>.

There are various models of care and several clinics and services who serve this population including: renal, rheumatology, cardiology, dermatology, sexual health, oncology, respiratory, gynaecology, diabetes, public health and mental health. However, in our local experience, there may be limited engagement between specialties.

Advances in technology, including social media and health apps, provide potential future opportunities for engaging and working with adolescents, and there are opportunities to develop evidence and experience of using these methods<sup>6</sup>. The 'Young People' section on Healthtalk.org, the patient experiences website, has modules on a variety of chronic and acute health concerns of this age group<sup>12</sup>. There are increasing ways to utilise the internet and social media to support health care specifically for this digital native population<sup>13</sup>.

To consider some of these issues, and with the support of the Sheila Kitzinger Programme, we held a multi-agency conference to share experiences and learning needs identified around adolescent health care, including transitional care. We aimed to consider what adolescence means to young people in the context of the changing world around them and how that influences perceptions of health and healthcare. We were able to bring together experts in the field, youth advocates and health champions, service users, researchers and commissioners, to share experiences and develop ideas and networks for resource development and sharing. We asked participants to consider: how to share ideas between specialist departments and the journeys and needs of young people accessing care through different parts of the health system; how we can hear about their needs and views; how we can adapt and develop health systems to meet young people's needs; and how we can make health services acceptable to them. As we considered and recorded these discussions and reflections, this report becomes also a report of active stakeholder debate and consideration, and as we invited participants to identify future service and research needs, it is our hope that it will be used to support or form part of a patient and public involvement exercise to develop research and service development in this field.

The meeting was attended by 50 delegates, including representatives from primary care (including safeguarding lead for the Oxfordshire Clinical Commissioning Group), from secondary care (including gynaecology, paediatrics, dermatology, paediatric rheumatology, renal medicine, and child and adolescent mental health), psychologists working with young people, specialists in adolescent and transitional care, researchers working in the field of adolescent health, researchers in education and experimental psychology, young peoples' advocacy charities, and young people (some of whom attended and spoke during the meeting, and some whose views we gathered prior to the meeting as described below, and presented to the meeting).

### Preparation for the meeting

It was important to us that this meeting about young people involved young people. We were fortunate to be able to involve some young people during the meeting itself, however we also wanted to ensure that the meeting was informed by the views of representative young people who can often find it difficult to share their thoughts in large groups of adults. As a result of this, and because the meeting was during a school day, in order to capture a range of thoughts and experience about what was important to young people about health services, we describe below

how we involved them in shaping the meeting, including setting priorities and influencing the questions we put to our delegates. We held two online video-chat (Skype) focus groups, and attended two Oxford state secondary schools, and a Woodcraft Folk youth group, to speak with young people about what they wanted from health services, where they wanted health services to be located, how they would like to access them, and what they thought were priorities for health services. We developed an interactive lesson plan (included as appendix A), and using this, we attended two schools, where we spoke to four groups of mixed age secondary school students, and one youth group. The findings from this stakeholder involvement part of the project are included in the appendices, and we used a summary of what young people had told us was important to them about services as the basis for discussion during the interactive part of the meeting. We hope that these findings will be used as patient and public involvement following on from this meeting, and by publishing them with this report are making them available for others to use to support research development. We therefore included the views of over 50 adolescents and young people from these meetings.

### Text box 1: Qualitative interviews with the young people

Qualitative researchers (Dr Abi McNiven and Dr. Suman Prinjha) conducted two online focus groups to explore young people's experiences of healthcare and the information that they would like from their GP. A semi-structured topic guide was used to prompt discussion. Six participants took part in the discussions, all of whom had taken part in qualitative interviews with the researchers in the past. Each focus group lasted about 90 minutes. Participants were asked:

- 1. When it comes to my health, the most important thing to me is:
- 2. What does 'health' mean to you? What does it include?
- 3. If a doctor was here right now and you could ask any questions you like, what would be your most important questions?
- 4. Is there any other information you'd like to get from a doctor?
- 5. When it comes to health, what do you think are the biggest topics that young people want to know about? What are the main questions?
- 6. If we wanted to ask more young people about the questions they'd really like to ask a doctor, how should we do this via social media? What is the best way to do this?
- 7. What advice would you give to a doctor who wants to specialise in working with young people?
- 8. What advice would you give to professionals who design and plan services (what would you like to see more/less of)?

### The programme for the day:

Programme for adolescent day Tuesday 17th October, Green Templeton College, Oxford

10.00 - Welcome to the day

#### 10.05-10.50 Plenary session, Chair: Dr Mina Fazel

"Twenty-first century adolescence - implications for health", Professor Russell Viner, Professor in Adolescent Health, Institute of Child Health and Reader in Adolescent Medicine, University College London

# 10.50-11.35 Session 1: Sharing experiences and challenges, some professional perspectives, Chair: Dr Abi McNiven

- 10.50-11.10 "Ready Steady Go: Delivering patient empowerment, shared decision making and transition" Dr Arvind Nagra, Consultant Paediatric Nephrologist and Lead on Transition, Southampton Hospital
- 11.10-11.20 "Experiences and challenges managing adolescents with renal disease" Dr Harden, Consultant Nephrologist and Daley Cross, Youth Worker, Oxford
- 11.20-11.25 "Setting up an adolescent Skin clinic, experiences and challenges" Dr Tess McPherson, Consultant Dermatologist, Oxford
- 11.25-11.30 "Mental health services in schools" Dr Mina Fazel, CAMHS consultant and associate professor Department of Psychiatry, University of Oxford

# 11.40-12.30 Session 2: Sharing experiences and challenges: some clinician and young people perspectives, Chair: Dr Tess McPherson

- 11.40-11.55 "The role of the GP in adolescent health", Dr Marian Davis, Chair of the RCGP Adolescent Group
- 11.55-12.10 "Examples of good practice in young people's health" Emma Rigby, Chief Executive of the Association of Young People's Health
- 12.10-12.20 "Mental health, Owl be positive" Aphra Tulip
- 12.20-12.30 "Social prescribing and volunteering" Devan Witter

#### 12.30-13.10 LUNCH

#### 13.10-14.30 Session 3: Moving forwards, Chair: Dr Sharon Dixon

- 13.10-13.30 "How can we use Healthtalk.org to educate medical professionals?" Dr Abi McNiven Qualitative Researcher at the Health Experiences Research Group, University of Oxford, Dr Suman Prinjha, Senior Qualitative Researcher at the Health Experiences research Group, University of Oxford.
- 13.30-14.30 Interactive session adolescent health where next?

#### 14.30-14.45 COFFEE

# **14.45-15.30 Session 4: Developments in adolescent healthcare** Chair: Dr Suman Prinjha

14.45 -14.55 "The state of training amongst health professionals for adolescent and transition medicine and strategies for improving skills" Emma Howard, Consultant Dermatologist, Birmingham Children's Hospital and Helena Gleeson, Consultant Endocrinologist, Birmingham

14.55-15.00 "Whistlestop tour of the commissioning process" Lajla Johannsen, Senior commissioning manager for Children's and Young people's services, Oxfordshire Clinical Commissioning Group.

15.00-15.30 Closing Plenary: "Adapting child, family and young people services to meet the needs of young people: the Norfolk Youth Service" Dr Jon Wilson Consultant Psychiatrist Youth / El Research Director (NSFT) Clinical Senior Lecturer (UEA) Norfolk and Suffolk NHS Foundation Trust and Dr Timothy Clarke Research Clinical Psychologist & CFYP Research Development Lead NIHR CLAHRC Fellow Clinical Advisor – East of England Clinical Networks - NHS England (Midlands & East (East))

15.30-15.45 Closure, and considering what now? Dr Mina Fazel CAMHS consultant, associate professor Department of Psychiatry, University of Oxford and Dr Sharon Dixon GP and NIHR In practice fellow, Nuffield Department of Primary care Health Sciences, University of Oxford.

### Summary of the day

We were grateful for the energy and enthusiasm all participants brought to the meeting. We were delighted to welcome a wide range of participants from backgrounds including primary care, education, psychiatry, dermatology, paediatrics (including paediatric nephrology, and rheumatology), experts in transition from both adult and paediatric services, experts in education, mental health, psychology and service design for young people, general practice, gynaecology, young peoples' organisations and advocacy organisations, young people as health advocates and campaigners, researchers working in the field of adolescent health including in education and young people in care, and a commissioner from the Oxfordshire Clinical Commissioning Group.

Below is a summary of some key points from the speakers' sessions.

### The opening plenary:

"Twenty-first century adolescence - implications for health", Professor Russell Viner, professor in adolescent health, University College London

- There is an important shift that we need to be aware of in the changing demographic of
  adolescence and the need to address adolescent health needs that was not the case at the
  inception of the NHS. Services need to evolve to match this social change.
- Adolescence is a time of significant biopsychosocial change. The data generated from studying paediatric and adult populations may not be representative of adolescents. In health terms, pathology often occurs at times of rapid physical change and development, therefore highlighting the importance of studying adolescence in and of itself.

- The demographic shift has led to a significant change in the burden of disease. When the NHS was founded, childhood was a time of significant pathology, largely related to communicable diseases, and service design reflected this. At that time adolescence was a relatively healthy life stage. This is no longer the case, and there has been a shift towards non-communicable diseases with adolescents now being less "healthy" than children.
- The pubertal growth spurt, and the associated changes that occur seems to be unique to humans. We ignore the growing science and understanding on adolescent physical and cognitive development at our peril.
- Adolescence is an important time in regard to the onset of risky behaviours that can affect health throughout the lifecourse, including beliefs being formed and behaviours relating to smoking, alcohol, drugs, and sexual relationships starting in adolescence. It is also an important time for the development of other behaviours which are important for health, such as self-management of health and illnesses, including healthy eating, and self-regulation and determination. Adolescence is a key time when behaviours that affect health, such as smoking and drinking, are initiated. It is also a key time when behaviours that determine how individuals manage their health and well-being develop, including involvement in their health and care, and eating behaviours.,
- Three key challenges for today's adolescents are: poverty, mental health, and obesity.
- Services that manage chronic illness need to consider adolescent needs, and be tailored to this.
- Calls for services to care for young people aged 0-24 and holistic services that capture the needs across the developmental years.
- In the Millennium cohort study, of the 16% of individuals with long term conditions, 40% of these had significant mental health problems.
- Reflected on whether there is a mental health emergency amongst young people. It is
  unclear whether what we are seeing is an increase in incidence or an additional component
  of added distress experienced by young people from the same rates of symptoms.
- The Lancet commission on adolescent health highlights the importance of education to promote health and to establish youth networks <a href="http://www.thelancet.com/commissions/adolescent-health-and-wellbeing">http://www.thelancet.com/commissions/adolescent-health-and-wellbeing</a>

#### Session 1: Sharing experiences and challenges, some professional perspectives

"Ready Steady Go: Delivering patient empowerment, shared decision making and transition" Dr Arvind Nagra, Consultant Paediatric Nephrologist and Lead on Transition, University Hospital Southampton NHSFT

- Young people need to be empowered to manage their long-term conditions. The Ready
  Steady Go programme can help improve the knowledge and ability for young people to take
  responsibility about their health conditions as well as for their parents and carers.
- The Ready Steady Go programme supports young people in developing their ability to take responsibility for their health and to plan for and support them during the process of

- transition to adult services. It also is a tool that helps the clinician, young person and their carers better navigate adolescence.
- Using the questionnaires provides a structured process that creates a space for young
  people and their clinicians to ask difficult questions and allows young people to ask
  questions about things that they might otherwise have not known to ask, or had the
  opportunity to ask, such as about whether their condition or medications may have any
  interaction with sexual activity.
- Dr Nagra believes that clinicians working with young people should write directly to young people from age 14 and copy parents in, to promote the ownership of the condition by the young person.
- The Ready Steady Go Programme starts from age 11.
- The active support with transition has increased appointment attendance and has halved inpatient admissions.
- Ready Steady Go are developing resources that will allow young people and clinicians to manage on-line records and patient owned clinical records.
- Ready Steady Go has central resources of information, and a generic programme applicable across specialities.

#### "Experiences and challenges managing adolescents with renal disease" Dr Harden, Consultant Nephrologist, Oxford University Hospitals NHSFT and Daley Cross, Youth Worker, Oxford

- It was noted that, for young people who had had renal transplantation, there was a very
  high risk of graft loss following the transition of the young person from children to adult
  services.
- They set out to transform services to develop an adolescent focus and more holistic meeting
  of needs and matching this to the provision of services, including youth-led support and
  education.
- They developed a better interface between paediatric and adult clinics, set up joint clinics, and made sure the team met young people before their transfer between services.

  Integrating a youth worker into service greatly supported this.
- The team have developed a model of care based around flexible community based young adult clinics.
- This has resulted in a highly significant reduction in graft loss.
- Young adult patient community clinics are developed to suit young people, for example, they have run clinics in youth centres, and at Glastonbury music festival. Their aim is to go to where young people are.
- This programme has brought together a community of young people who have experienced renal transplantation and this has facilitated peer-to-peer support and engagement.
- The programme has improved outcomes, including better satisfaction and health outcomes.
- Young people have been involved in designing the service, including recruiting the project youth worker. The youth worker is not a clinician, and works to understand and facilitate meeting young peoples' needs.

### "Setting up an adolescent skin clinic: experiences and challenges" Dr Tess McPherson, Consultant Dermatologist, Oxford University Hospitals NHSFT

- Dr McPherson has established a dedicated clinic for young people with skin problems.
- A key part of her clinic is to the involvement of a clinical psychologist.
- She notes that the clinic has good outcomes, but that the challenge of maintaining psychological support to young people with long term conditions and complex needs remains.
- The impact of the visible nature and stigma associated with skin disease can be really difficult for adolescents. It can impact on self-esteem, which may be low in any case. Skin problems can make young peoples' lives harder and may restrict what they feel able to do.
- Dr McPherson notes that we need a range of different approaches and that we need to learn more about how to support vulnerable teenagers with difficult skin conditions impacting on their lives.

# "Mental health services in schools" Dr Mina Fazel, Associate Professor in Child and Adolescent Psycahitry, University of Oxford and Consultant Child Psychiatrist, Oxford University Hospitals NHSFT

- Mental health is a serious problem of great importance to young people. Mental health services need to become more accessible to the majority of young people with mental health problems.
- To try to address this, , with support of CCG, Oxford CAMHS has developed an InReach service, where mental health professionals visit their allocated school on a weekly basis to improve joint working with professionals in the education setting and to improve access for young people.
- Working in schools allows mental health specialists to better support staff in schools and
  work with them to ensure that the mental health issues of young people are addressed as
  early as possible, as teachers are often the first port of call for young people and families in
  distress.
- Working in schools can democratise access to services but the best models of community care still need to be clarified and studied.

# Session 2: Sharing experiences and challenges: some clinician and young people perspectives

"The role of the GP in adolescent health", Dr Marian Davis, Chair of the RCGP Adolescent Group

"The role of the GP in adolescent health", Dr Marian Davis, Chair of the RCGP Adolescent Group

- Adolescents do use primary care services, contrary to popular belief 50% of 12-18 year olds have seen their GP in the previous 3 months 75% in the last year
- Adolescents are often given less time than others when they come to see a GP( two minutes less per consultation)
- Most adolescents' health needs are met entirely in primary care
- The GP already has a relationship with the adolescent and their parents and so can have a pivotal role in the transition to adulthood e.g. self management and consulting alone

- Young people often have their own agenda- this may differ from the parents agenda
- There are challenges when working with young people and their parents, particularly in supporting and maintaining relationships with both. It is important to maintain trust and confidentiality for young people. We need to remember that parents can be both protective and risk factors, allies or barriers.
- Advises that doctors should always try to see young people alone, in order to hear their story. It can help to explain this to parents in the context of privacy and supporting their young person in developing the skills to learn to look after their own health and making it the norm for the final couple of minutes of every consultation.
- Explain confidentiality and its limitations to a young person in the presence of their parent.
- GPs are the key record holders, which is a crucial role in safeguarding.
- Continuity of care and longitudinal relationships allow trust to develop and stories to unfold. Sessional work may mitigate against this.
- Advised factors to consider to make general practices young people friendly and safe: for
  example, considering access to appointments and medications, computer access to their
  own records (but switch off from parents at age 12), birthday invitation letter, community
  outreach clinics, and teaching in schools about how to access health. Have a system for
  following up on DNAs, record a young person's mobile phone number
- Notes should be coded for potential vulnerabilities. The GP can be a significant adult in the life of more vulnerable children and young people.
- GPs should talk to the child rather than the parent from a young age
- Timely interventions at this developmental stage can have long term benefits in all aspects of life
- Healthy behaviours can be established
- Long term mental health problems can be prevented
- Appropriate use of health services can be encouraged

# "Examples of good practice in young people's health" Emma Rigby, Chief Executive of the Association of Young People's Health.

- There are frameworks for developing good practice in young peoples' health.
- "you're welcome"
  - (https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/216350/d h\_127632.pdf) provides quality standards for young peoples' health services.
- Advocates that we should involve young people in care design and delivery of services.
- Young people want services in the age range from 10-24 years.
- There are good models of co-production, such as young peoples' take over days. It is important that these are accompanied by the meaningful use of data generated.
- App called NHS Go. Provides free and confidential information about accessing services. (https://nhsgo.uk/)
- Resources include a compendium of case studies on prevention work in voluntary sector.
- Need to engage schools and the voluntary sector.
- Resources developed include toolkit for general practice, champions for youth projects, 10 easy things any service can do to improve services.
- Red Thread charity is a charity based in London that seeks to bridge gaps between youth and health, work and education. They developed the Well centre model, in response to listening to young people's concerns about the accessing healthcare. http://www.redthread.org.uk/

#### "Mental health, Owl be positive" Aphra Tulip, Young Person Representative

- Asked for professionals to be aware of the negative assumptions that they can make about people and that adolescents might be particularly sensitive to these.
- Talked about fear of accessing services but also described positive interactions that helped her.
- Importance of being able to become an advocate /champion for young peoples' health.

#### "Social prescribing and volunteering" Devan Witter, Young Person Representative

- Role of volunteering helps others help young people, also helps the person volunteering
- Young people often excluded from social prescribing, especially those with health problems, but actually might be of greatest benefit to this group (who might also be excluded from other types of employment)
- Importance of reflecting what young people do and formal accreditation to recognise the contribution and commitment of young people in the third sector, for example with certificates that they can then show to prospective employers.
- Should prescribe volunteering to young people.

#### **Session 3: Moving forwards**

"How can we use Healthtalk.org to educate medical professionals?" Dr Abi McNiven and Dr Suman Prinjha, University of Oxford

- Listening to and understanding young people's experiences can help improve care and services for them. The Healthtalk website (<a href="www.healthtalk.org">www.healthtalk.org</a>) provides free, reliable information about health issues based on people's personal experiences.
- Created in 2001 by Oxford GP Dr Ann McPherson, it now covers over 100 health topics. 16 studies are specifically about young people, including experiences of skin conditions, diabetes, depression and low mood, and sexual health. All 16 young people's sections contain detailed information about how participants experience healthcare.
- Dr Prinjha showed a short video montage from her study about young people's experiences of seeing the GP (completed in 2017 and available at: <a href="http://www.healthtalk.org/young-peoples-experiences/seeing-gp-advice-and-tips-young-people/topics">http://www.healthtalk.org/young-peoples-experiences/seeing-gp-advice-and-tips-young-people/topics</a>).
- 34 people were interviewed for this study on young people's experience of seeing the GP and the site covers 36 of the most important topics to them. The main themes from the research are presented as 'topic summaries' and illustrated with around 250 video/audio clips from people's interviews. Participants talked about seeing the GP about minor issues, long-term conditions, mental health and sexual health. Young people also discussed what was helpful and challenging when it comes to seeing the GP.
- Seeing the same GP every, or almost every, appointment was important for people with a long-term condition or mental health issue, but not only for these participants. Young people talked in detail about what made a good consultation versus a bad one, including the qualities of the GP. A doctor that listens, speaks directly to them and not their parent, and takes concerns seriously were also key themes, as well as whether young people could see

- the GP on their own, without a parent, and whether these appointments would still be confidential. Young people also asked about the situations that doctors might breach confidentiality.
- Young people discussed their views on how services could be improved, how they felt about telephone, email and Skype consultations, and at the end of the interview they gave messages to GPs and other young people.
- An interview with a GP was also included on the site, providing information about privacy in appointments; young people's rights; the kinds of problems that GPs can help with; and what to do when local surgery GPs are unavailable.
- The 34 interviews were also used to produce 2 short trigger films aimed at promoting discussion. They can be found on the Healthtalk website and on YouTube. One film focuses on young people's views of online medical records, and the other on their views of using technology to access GP services.
- Dr McNiven presented a guide to using the 'Scrapbooking' facility on the Healthtalk.org website. This facility allows anyone who registers with the Healthtalk.org site to create their own resource using the video, audio and text-only clips available on the website. A user chooses their own clips from any 100+ health conditions featured on the Healthtalk.org website and to order them as required, as well as provide an optional description of the purpose of the Scrapbook. This gives flexibility about the remit of the topic for the Scrapbook and the uses, for example as suited to particular topics and purposes in medical education and training. Scrapbooks can be kept private, shared with a selection of people or made publicly available; publically-available Scrapbooks can also be viewed by other visitors to the website. The guide was illustrated with several example Scrapbooks produced by Dr McNiven from the skin condition modules (acne, eczema, psoriasis and alopecia areata).

#### Interactive session adolescent health where next?

In this session, we asked all the meeting participants to work together in small groups to consider their thoughts on the following questions:

- 1. What achievable changes to services would you suggest? What changes can you make now? What would you like to change or develop?
- 2. How and what can we learn from young people? How can we involve them in service design and development?
- 3. What research or information would help improve services or young people's health experiences and outcomes? How could research help and what research or information is needed?
- 4. What are potential barriers to developing adolescent services?
- 5. What are potential facilitators to developing adolescent services?
- 6. What support or information do 21st century parents and professionals need to support 21st century adolescents...



To support their discussions, in addition to all that we had heard and learnt throughout the morning, each group was given a summary of what we had heard from the young people we had spoken to prior to the meeting, explaining what they wanted from health services (copy included as appendix D). Each group wrote their discussion points and comments on post it notes, and these were reviewed in discussion amongst the whole group. The postit notes are transcribed verbatim, and included as appendix E, however the key themes are summarised below.



- Service Design: Achievable changes in terms of service design included involving young
  people in the design and delivery of services; increasing the psychological support offered;
  involving GPs in transition planning and the care of long term conditions; and allowing dual
  GP registration for young people with health conditions who live between locations, because
  of work or studying.
- 2. **Timing and mode of appointments:** Taking steps to make services accessible to young people included considering the timing of clinics and appointments; how appointments were booked or arranged, including considering alternatives to face to face consultations; and where clinics and appointments were offered.
- 3. **School relationships:** Working to create stronger links with schools to provide services and promote health was identified as an important aim, including seeking to commission education in schools to help young people understand how they can access health advice and healthcare. An example of how this could be supported would be to use the RCGP PSHE

- lesson plan, which could be delivered in schools by GPs or school nurses, with the support of CCGs.
- 4. **Environment changes:** Making the health care environment "young person" friendly, for example by providing free wifi, age appropriate resources, magazines, and information in waiting rooms, was an example of changes that could be made to healthcare settings.
- 5. **Communication issues:** Changes that could be made to how we communicate with young people as professionals included considering confidentiality, and how we explain this to young people; developing skills in speaking to young people alone, including offering them choices about whether their parents were with them or not; and learning to normalise speaking to young people alone as part of every health encounter. This could be supported by training and support for professionals working with young people.
- 6. Co-production of services: Learning from and involving young people in services was identified as a key aspiration across all aspects of healthcare. Ways of involving young people in service development included ensuring that young people were represented in patient participation groups, and executive boards; and that they could be involved in speaking to young people, and in recruiting staff to work with young people. Consulting with existing groups, such as youth parliaments, scouts and brownies was felt to be valuable, but also seeking to reach out to and hear from 'hard to reach' groups and individuals was crucial. A key part of involving young people includes not only asking questions, but listening to the answers and acting on the results; being prepared to be challenged by the views of young people; and considering doing things differently. Ways of reaching out to young people included face to face conversations, but also using social media or targeted feedback surveys, and being able to learn from complaints about services made by young people. Involving young people in research about them is central to understanding their needs and striving to improve services. Young people need to be involved in all stages of research, from considering the questions that research seeks to develop understanding about, designing how research is carried out, to being involved in doing the research and interpreting and disseminating findings.
- 7. Identifying research priorities: When asked to consider research priorities, the importance of involving young people throughout the process was stressed. Priorities for research included: understanding how young people access services, including ways of reducing the stigma or shame associated with this (for all services, not only mental health); understanding the needs of minority groups; exploring how young people first access health services, and how and why they choose to do so; how primary and secondary care can interact more effectively when caring for young people; and the role of social prescribing. There is a need for practical research that can make a difference. A core question identified was what important outcomes are in the field of young peoples' health interventions. Concerns were raised that short term outcomes (while potentially more measurable) may not capture the benefits of interventions on outcomes that could be valuable to young people and the societies in which they live. Examples of potentially important outcomes include employment at age 30, or adult lifestyle behaviours and health behaviours. Concern was raised that, without considering longer term outcomes, we may underestimate the value (and cost-effectiveness) of early interventions, and of investing in young people. Understanding what outcomes matter and how these can be measured was central to the debate around this question. When considering how research could be done, the need to

- use and develop age appropriate research tools, and then the value of sharing these between disciplines once developed, was identified as an important research need. Developing ways to centralise data, and to share good practice and resources to optimise the involvement of young people in research, and share data and tools for example to manage processes of consent and recruitment, would be valuable. When research is done with young people, disseminating and implementing the findings is vital.
- 8. Considering adolescent needs systemically: Potential barriers to developing adolescent services raised were the limited understanding of adolescents' health needs by managers (and clinicians), including considering only short-term outcomes, and disregarding the long term benefits of investing in young peoples' health. The existing culture of adult and paediatric services can make creating a new space for young peoples' care difficult. The way in which services interface with each other can make care discontinuous and the between specialist services (including super-specialists) and between primary and secondary care, or between physical and mental health providers. Changes in the way services are delivered that compromise continuity of care, for example the move towards sessional care in primary care, could create challenges for young people learning to manage their health care and develop trust in professionals. There are ways in which the ways health services are organised and in legislation that can be barriers for young people, for example in not allowing dual GP registration for young people attending higher education.
- 9. Training of professionals: The involvement of young people was central to facilitating the development of youth services. This includes involving them in educating health professionals, and developing professional champions to promote an understanding of how to work with young people. Both professionals and young people have potential important contributions to play as role models. Young people leading the way in developing peer support for other young people (with professional support) would be valuable. Organisations that could help include schools, charities and voluntary groups, social prescribing, and the clinical leads in clinical commissioning groups. Having age appropriate information, available through a central easily accessible resource bank would help young people seeking healthcare, and also support the professionals who are caring for them. There is a need for primary and secondary care to seek to work collaboratively, with communication and information sharing, to develop individualised care for young people, that can be communicated throughout their care journey.
- 10. **Information:** To support 21<sup>st</sup> century adolescents, parents and professional needs identified included understanding and then delivering youth friendly services. We need to understand what this is, and how to deliver it but ideas raised included developing and providing age appropriate information, peer support, the greater use of youth workers, training in delivering developmentally appropriate healthcare for health professionals and all healthcare students, and support for parents and schools. Care needs to be inclusive and holistic. Training in communication, and clarity about confidentiality and consent could promote the development of trust in health professionals.

#### Session 4: Developments in adolescent healthcare

"The state of training amongst health professionals for adolescent and transition medicine and strategies for improving skills" Emma Howard, Consultant Dermatologist, Birmingham Children's Hospital and Helena Gleeson, Consultant Endocrinologist, Birmingham

- There is a training gap; trainees are not given experience or able to develop experience to deliver developmentally appropriate healthcare. This requires facilitation of appropriate parental involvement, good communication with young people and encouraging them to make decisions about their health care.
- All Royal Colleges need to address the need for all professionals to receive training in understanding the need and delivering developmentally appropriate healthcare. This can be achieved by changes in curriculum and providing appropriate training.

Link to evidence base: http://research.ncl.ac.uk/transition/

Link for tools for training: <a href="https://www.northumbria.nhs.uk/dahtoolkit">http://www.youngpeopleshealth.org.uk/yourewelcome/</a>

"Whistlestop tour to the commissioning process" Lajla Johannsen, Senior commissioning manager for Children's and Young people's services, Oxfordshire Clinical Commissioning Group.

• Explanation of commissioning cycle

Importance and value of practitioners collaborating and co-constructing service development to address adolescent needs in healthcare.

Closing Plenary: "Adapting child, family and young people services to meet the needs of young people: the Norfolk Youth Service" Dr Jon Wilson Consultant Psychiatrist Youth / El Research Director (NSFT) Clinical Senior Lecturer (UEA) Norfolk and Suffolk NHS Foundation Trust and Dr Timothy Clarke Research Clinical Psychologist & CFYP Research Development Lead NIHR CLAHRC Fellow Clinical Advisor – East of England Clinical Networks - NHS England (Midlands & East (East)

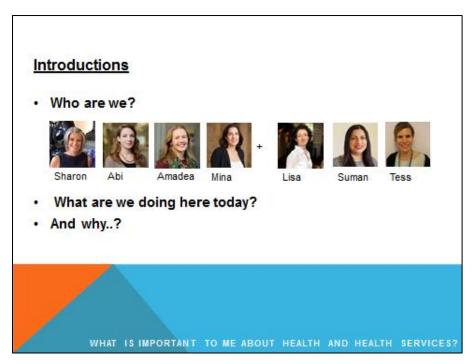
- Social recovery model of care
- Aware that needs of this age group were not being met, and falling between service
- Average of 5 pathways, not integrated care
- What young people want is a one-stop shop.
- Involved young people and extensive stakeholder work to develop and design services.
- Multiple ways service can be accessed, reduced complexity in system
- Built a 0-25 service, 0-14 family focus, 16-25 youth wellbeing team, anyone can refer into.
- Need a trans diagnostic conceptualisation of need for this group.
- Not transitioning many into adult services at age 25.

Closure, and considering what now? Dr Mina Fazel CAMHS consultant, associate professor Department of Psychiatry, University of Oxford and Dr Sharon Dixon GP and NIHR In practice fellow, Nuffield Department of Primary care Health Sciences, University of Oxford.

- Reflect that there is a balance between empowering young people, and supporting them to develop their own sense of autonomy for their health, and remembering that as professionals we have a duty to protect and safeguard on them.
- Reflected upon the Bullfinch case in Oxford, a Child Sexual Exploitation ring. The subsequent serious case review found that too often, young people were treated as young adults, and their vulnerabilities were not recognised.
- Key to any safeguarding, or any support of young people, is being able to develop services where they are able to come, and feel able to speak. Without this, there are only missed opportunities to both protect and support.

#### Appendix A: Lesson plan Powerpoint slides



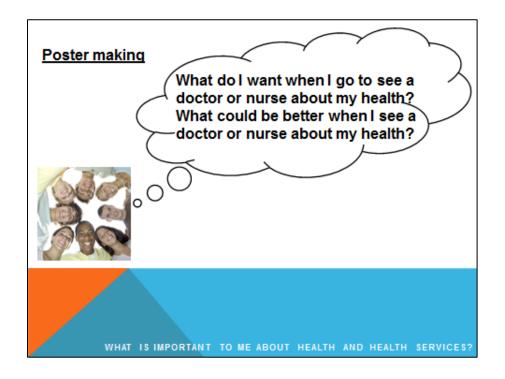




#### **Discussion:**

- · What does 'health' mean to you?
- · What does 'health' include (or not include)?
- · What things promote 'health'?
- What makes 'health' harder to achieve?

WHAT IS IMPORTANT TO ME ABOUT HEALTH AND HEALTH SERVICES?



## What do I want when I go to see a doctor or nurse? What could be better when I go to see a doctor or nurse?

Some ideas/things to think about for the poster...

#### Daisy

Daisy is upset about having acne on her back. She also wants some advice on contraception.

#### Nick

Nick has had type 1 diabetes since he was little. He is going to university next year. He wants to know how he can see doctors and get medical care when he moves away from home.

#### Molly

Molly hurt her ankle playing sport and it's very painful. Her mum is at work and can't take her to the doctors.

#### Chris

Chris is very worried about his exams and he's finding things difficult. He is struggling to concentrate and not sleeping well.

WHAT IS IMPORTANT TO ME ABOUT HEALTH AND HEALTH SERVICES?

# What do I want when I go to see a doctor or nurse? What could be better when I go to see a doctor or nurse?

Some ideas/things to think about for the poster...

What are the good things my doctors and nurses have done for me? What things could my doctors and nurses do better for me?

What do I do when I want to see a doctor or nurse?

Is the doctor or nurse friendly?

When do I want to see a doctor or nurse? How often?

What are the receptionists like?

How do I get to the doctors? How long does it take me to get there?

What is the waiting room like?

Who do I want to see? E.g. GPs, nurses, hospital doctors, counsellors, etc.

How are things explained to me by the doctor or nurse?

Do I want to take someone into the appointment with me or go alone?

I wish my doctor knew...

WHAT IS IMPORTANT TO ME ABOUT HEALTH AND HEALTH SERVICES?

#### **Discussion**

- What messages do you have for doctors and nurses?
- · What questions would you like to ask doctors and nurses?
- What messages do you have for the people who design and plan health services?
- What questions would you like to ask the people who design and plan health services?
- · Anything else?

WHAT IS IMPORTANT TO ME ABOUT HEALTH AND HEALTH SERVICES?

#### Next steps...

- · Young person's advisory panel
- A workshop in Oxford in 17<sup>th</sup> October: 'What does it mean to be an adolescent in the 21<sup>st</sup> century? Implications for health and healthcare'

### Thank you!

Any questions or comments?

WHAT IS IMPORTANT TO ME ABOUT HEALTH AND HEALTH SERVICES?

#### **Appendix B: Feedback from schools PPI**

#### **Education and information**

- Taught about mental illness
- Taught how to support others with mental illness/respond to them
- Teach them about all aspects of health, not just physical
- Education about how to access health, and how to make a doctors appointment
- Start teaching children when they are young

- Education about range of health issues and things people could have
- Targeted information leaflets
- Support for people scared of needles
- Reducing association of health with place where have needles or are uncomfortable
- Trusted website where can get health information specific to adolescents
- Resource lists that can be accessed e.g. in libraries
- Posters and information to be positive and inspirational

#### **Access**

- Can come about anything, can come without parents
- Phone app to book appointments and get advice
- Want on line booking
- Training for receptionists/not having to speak to or justify with receptionists
- Friendly receptionists
- Inviting and supportive and easy access
- Mixed views on email or facetime access
- Not being asked to come back another day

#### Communication

- We heard a range of views about whether on line or one to one communication with doctors would be helpful or not
- Want a choice of pronouns and inclusion of non-binary gender forms of address and for professionals to recognise and respect and use different choices

#### **Priorities**

- Young people want to have a say in designing services and how to access
- Confidentiality including about appointments and their medical records which they did not want others to be able to access or see
- Sound proof rooms
- Pay nurses more
- More doctors
- Not long waits for an appointment when they want to be seen
- Access without parents knowing or needing to be involved
- More experienced school nurses, and good first aid in schools
- Access to exercise and places to go
- Want smiles from staff!

#### Features of service design:

- Wifi in the waiting room (questions were asked about privacy and confidentiality)
- Up to date information about times and running late
- Mixed views on whether in school (access and privacy from parents) or not in school (privacy enhanced by distance, no-one at school needing to know, not wanting to miss lessons, corridor of shame...)
- More frequent check-ups (would build trust and develop relationships)

- Friendly atmosphere, welcoming waiting room, not all scientific posters, colourful and bright, beanbags/comfortable. Not white...
- Want a waiting room where ill people not mixed in
- Want drop in clinics after school
- Want a health advice service
- Therapy pets
- Vending machine or café in the waiting room
- Things to do in the waiting room (wifi, games, newspapers pool table!)
- School support and advice for stress
- Drop in anonymous sexual health services

#### Things about professionals:

- Be able to give social advice
- Be approachable and friendly
- Explanations about what will happen and what they will do
- Being able to choose to see a younger doctor or a female doctor if want to
- Help people feel they are not the only person with this problem
- Being able to see people other than doctors for health advice
- Not being patronising

# Appendix C: Summary of key points from 2 Skype focus groups with 18-25 year olds (total 6 participants)

#### **Mental health**

- Recognition that mental health is as important as physical health, and a subject that is of high priority to young people.
- Mental health services and information about mental health is vital. Non-university and non-school based psychological support should be available and clearly signposted to.
- > Students should be told about the range of counselling services available, internally and externally, so that they can choose what is best for them. There is sometimes a stigma around being seen to be using university or school counselling services.
- Being a teenager is stressful. Mental health problems need to be addressed as quickly as possible. They need to be a priority and referrals made quickly.
- > It is important to be seen as a young person, not a condition or set of symptoms.
- More information about the signs and symptoms of anxiety and depression.
- ➤ More information about managing stress, particularly before exams.

#### Sexual health

> Sexual health services at present are unappealing, yet very important and so they need revamping.

- Sexual health should also be integrated across all aspects of health care. For example, it's not okay to assume that young people with certain conditions (such as depression) are not in relationships or having sex. They need to be given information about how their medications might interact with contraceptives.
- More information about the range of contraceptives available (not just the pill) and the side effects of each.

#### Youth friendly services

- > Would include appointment times suitable for young people (e.g. it can be time-consuming to book appointments (and off-putting talking to receptionists who want to know why you're booking an appointment), long delays before an appointment is available, long waits in the waiting room for appointment and/or walk-in clinics.
- ➤ More flexibility with consultation lengths and formats e.g. double appointments, extended appointments, email consultations, telephone consultations, videochat consultations.
- > Booking appointments online is quicker, easier and saves having to speak to someone over the phone.
- Friendly and approachable medical professionals and receptionists.
- ➤ Easily accessible information which young people can look at again at a later date should they need to e.g. emailed records of consultations and photographs of leaflets
- Clinics specifically for young people (e.g. 5-7pm on a certain day per week) could be helpful.

#### Better coordination between primary and secondary care services

- The need for better follow-up care and test results.
- The need for transparency around referrals when/why/how? (i.e. more explanation about when they are made, why and the length of time it can take to be referred).
- ➤ Better communication between medical professionals at present, a lack of communication often means that young patients are left to coordinate it themselves and gather information. Shared online records could be helpful as well as the possibility of dual/multiple GP registrations in different places so that a young person can be registered at a GP clinic at university and home.
- More support for help young people to live as actively with a long-term condition as they can rather than just advice about the medication and things they might find difficult to do.
- > The logic behind treatment decisions needs to be explained. If there are a range of options, these should be explained and discussed so that young people can be involved in choosing. Shared decision-making is good but it needs to avoid placing sole responsibility onto patient (there should be a balance).
- > Jargon-free communication, information and explanations, including information about how to stay healthy. There is very little dietary advice in schools.
- > Set out a clear pathway (e.g. explain which treatments will be tried first and what will happen if they don't work).

#### **Information and signposting**

- Young people often learn about accessing primary care services informally. More information on this would be helpful and their rights to see the GP alone, without parents. This is often learnt about through friends.
- ➤ Help with navigating medical systems and services a road map.
- Signposting to charity support.

- > Smartphone technology (and free wifi) would help raise awareness of services available to patients with a range of conditions and concerns/needs (especially mental health).
- A small notice board in the waiting room with information that's relevant to 16-25 year olds (e.g. about contraceptive, mental health, and diet).

#### Key questions from young people to GPs

#### Mental health

Are GPs the first professional a young person should talk to about mental health? Who else is available to talk to if a GP appointment isn't available that week?

Why are antidepressants the first treatment that is offered by GPs and not a last resort?

Why isn't counselling offered before antidepressants?

Why aren't young people told about the range of psychological support available so that they can choose what's best for them, whether that's a psychological therapy or medication?

Can antidepressants affect the contraceptive pill?

Why aren't there more counsellors working in schools?

Why does it take so long to be referred for psychological support (e.g. CAMHS)?

#### **Sexual Health**

Why is it always such a long wait when you go to a sexual health clinic?

What are the various contraceptives that young people can use and the pros and cons of each?

#### Long-term conditions

Why do health professionals look only at the physical side of a long-term condition and not the impact it has on a person's whole life?

Why aren't young people signposted to other services when they have a long-term condition (e.g. those provided by charities)?

#### **Physical health**

When is it best to see a pharmacist instead of the GP?

What do you think is the future of the NHS and how will this affect young people?

What will GPs do in the future to improve mental health services for young people?

#### Suggestions for reaching a large group of young people

**Facebook** 

Instagram
Twitter
Go to a school assembly, and give a talk and form for people to fill out
School registration – form tutors sometimes give out questionnaires to fill out from external organisations
Appendix D: Feedback from school and focus group PPI amalgamated and as presented to groups at the meeting for discussion

#### Mental Health is as important as physical health

Want information about mental health symptoms and how to recognise and manage these. Want information about different treatment and services with choice. Services should available quickly when needed.

Want reduced stigma for mental health, treatment as individuals with dignity, respect, confidentiality

Want help with stress and managing stress (eg exams) in school

Want to be taught how to support their friends and peers

#### Communication and Information

Better communication about test results and explanations about examinations, tests and how long things will really take (eg referrals...)

Better communication between health professionals. Consider patient held records, shared on line records, shared care between home and uni

Jargon free communication, speak to the young person, explain the logic behind decisions and shared decision making (but share responsibility, not all on patient). Expectations of treatment and clear pathway of what next...

Non binary choice of genders on records and when consulting

Road map and education about how to find and use services

Support to help people live actively with long term conditions

#### Youth Friendly services

including appointments outside school times, drop in clinics after school, dedicated young people's clinics

Being able to arrange appointments on line, not having to talk to receptionists, flexible appointment format (eg on line, app) NOTE want CHOICE of face to face or alternatives

Young person friendly information, trusted resources, access to medical info on line. Info about other things for health such as exercise, diet, supportive charities. Want a dedicated information board about youth services in health settings and school, To be able to ask for health advice

Education about how to access services and appointments, including that you are allowed to go without your parents.

Friendly approachable staff, choice of doctor (gender,age)

#### Sexual Health is important too!

Services at present are thought to need re-vamping to be more accessible and welcoming.

Want to not have long waits to be seen I want drop in anonymous

Want sexual and contraceptive health to be integrated throughout physical and mental healthcare

More information about all contraception options, and no assumptions.

#### Service Design Suggestions

Wifi in waiting rooms! A friendly atmosphere with bright posters and comfortable chairs, and things to do while waiting..

Vending machines or cafes in the waiting room.

Up to date information about timing and delays. If a long wait, an app that let's you leave, and tells you when to come back.

Mixed views on whether better in school... or outside of school. Advantages and disadvantages identified for both.

More checks ups to build trust, help with not liking needles.

Resources in public places like libraries and targeted resources.

#### Priorities identified

Holistic care, including physical, mental, emotional and sexual health.

Holistic care for people living with long term conditions, advice beyond physical management.

Confidentiality, sound proof rooms

Involve young people in service design and access

Education about how to access health, including whether parents have to be involved and managing medical records and appointments.

Rapid appointments when need to be seen.

More doctors and better paid nurses.. Staff who smile and are friendly !

Places to exercise and places to go and be healthy.

#### Appendix E

- Question 1: What achievable changes to services would you suggest? What changes can you
  make now? What would you like to change or develop? Centralised information and
  resources
- 2. Telephone clinic in evenings (straight after school) 3pm onwards, GPs at youth clubs, flexibility going to meet needs of young people, rather than expecting them to come to us, alternatives to face to face consultations eg skype/video chat.
- 3. Confidentiality check mobile number fir apt text reminders in GP surgeries is this the parents of young persons number
- 4. Reach out proactively to invite young people in but think about relevance and motivation to come
- 5. You're welcome a great framework, just find a way in, ask young people to help.
- 6. Ask young people the question and wait for the answer
- 7. Moving services out of hospital and into the community (Glastonbury festival) 18-20 year olds don't want to be seen in a children's clinic (toys, bright colourful magazines) need separate environments or different stuff in the waiting rooms, timing of services –consider school day and travel run evening clinics like sexual health services do.
- 8. Education peer support and access to adult services, volunteering, visit social
- 9. GP led PSHE lessons in secondary school? Can commission.
- 10. Peer support for young people
- 11. Starting speaking to the young person from a very early age and introducing the choice (to be seen alone) in a very normal way, checking in regularly, choice to have parents with them or not, respect their wishes
- 12. Have user experience as the main outcome.
- 13. Exploring location of services eg Glastonbury etc
- 14. Build a GP into transition planning and onwards/long term condition care
- 15. Improved psychological support
- 16. Transition appointment with GP, yearly appointment with GP for young people who are looked after, as with learning disabilities, allow double registration (college or uni and home GP) for young people with LTC mental illness, vulnerable groups, coding vulnerabilities (contact Marian Davis for further info)
- 17. Involve volunteering services, feeling useful, peer support out of healthcare activities reduce stigma
- 18. Mechanisms for facilitating peer support that is not clinician led, volunteering
- 19. Create activities to keep you busy while waiting QR codes with information, health games, consultation embedded into games/activities, links to other services
- 20. Make (environment) more pleasant for everyone, free wifi, good lighting, info screens (friendly receptionists training)
- 21. Make first point of contact friendly, training recruitment using young people alternative communication options

- 22. Advising young people take photos and leaflets (private, stored info), reworking leaflets to be useful.
- 23. Rare diseases isolation, promoting shared experience, risks getting vulnerable people together vs benefits of connection
- 24. Access on line appointments including urgent, with facility to prioritise using questions, adolescent friendly environment, wifi, timing of clinics education about how to access healthcare, PSHE, strengthen links between GP and school.

Question 2: How and what can we learn from young people? How can we involve them in service design and development?

- 1. Increased engagement through schools to involve young people in development of healthcare
- 2. Representation and co-production respect, youth boards funding campaigns interviewing staff, include range of young people including those less likely to put themselves forwards/have the opportunities, young people collecting information from young people to feedback (more accurate positives and negatives) research designed with young people, not just about them.
- 3. Better signposting, one stop platform to sign post
- 4. Easy to ignore, engage and value the youthquake.
- 5. Ask them use schools, peer mentoring and social media
- 6. Accept the challenge of gathering consultation from 2hard to reach" young people not just those who won't participate, online surveys as well, be willing to be challenged by what the young people say/want it may not be what is expected but otherwise there is no point
- 7. Be sure not to ask young people the same things over and over again, patient participation groups, consult on health issues with existing groups, e.g. Brownies and Scouts, have youth steering groups on executive boards
- 8. On line psychological support service, need a spectrum of opportunities
- 9. Youthquake and e-technology
- 10. Young people's feedback group for GPs consider YP groups that exist
- 11. Use existing groups such as guides and scouts to reach more people, share the data collected avoid repetition of questions act on consultation results targeted satisfaction results.

Question 3: What research or information would help improve services or young people's health experiences and outcomes? How could research help and what research or information is needed?

- 1. Research long term benefits to improve health outcomes and initiate healthy behaviours, research the cost savings social care, impact on society, work, employment, families
- 2. Research tools fit for purpose e.g. mental health scores of questions vs clinical need
- 3. More research on stigma and shame for YP accessing health services (not just focussed on mental health holistic)
- 4. Research into minority groups reducing inequity and access to care, LGBT, ethnic minorities

- 5. Implementation of research findings, integrate physical and mental health
- 6. Sharing good practice, problems with recruitment and consent and parents, age appropriate re
  - Research, database issues good practice, Centre for Evidence Based Dermatology research disseminates well, dissemination of research and practical research.
- 7. Social prescribing what should outcome markers be to understand young people health (eg in employment at aged 30)
- 8. Research young people's agenda, are we asking the right questions, young people's role in doing research and interpreting results
- 9. Remember sometimes young people know a lot and sometimes it's blagging
- 10. More research on why young people first access health care services, targeted patient satisfaction survey for under 25s, consider responses to complaints
- 11. How do you get outcomes that capture things that matter/ know that your research or intervention has made a difference (e.g. employment at 30 as an outcome measure)
- 12. What do GPs want to know from specialists (and vice versa)

Questions 4/5: What are potential barriers to developing adolescent services (B)? What are potential facilitators to developing adolescent services (F)?

- 1. Think broadly about organisations who help, e.g. the Prince's trust F
- 2. Adolescents, social media, vloggers and influencers, improved training for professionals, adolescents in every curriculum exam, school F
- 3. Voluntary groups, charity groups, centralisation, using the right tools F (SD note what are the right tools. One for Q3)
- 4. Clinical leads on board to influence commissioning F
- 5. "wall of services and rules" not helpful e.g. adult B
- 6. Getting data in the right format e.g. age ranges F
- 7. Primary health care in schools F
- 8. Role models YP youth workers charities GPs F
- 9. Building up a critical mass of professionals who help YP. F
- 10. Meet adolescents/YP in medical training, champions of youth involvement, central resources for information. F
- 11. Social prescribing, getting people connected
- 12. Involve primary care in transition programmes such as ready steady go
- 13. Diversity YP not all the same B
- 14. Children go to uni and get a new GP for long term conditions even though spend 1/3 year back at home B potential for electronic records as a way to minimise this problem one day (F) but impact on rapport ? B
- 15. Re-labelling medications and adjusting associations eg CHC treatment for gynae and derm conditions but associated with bring for sexually active, parallel concerns.
- 16. Champions, and building better business case F
- 17. Rapidly developing services so want input but hard to keep up B
- 18. Barriers between different groups of services and professionals., B
- 19. Understanding who should and who should not pay for prescriptions. F
- 20. Legislation as a major barrier, e.g. safeguarding child vs YP B

- 21. Changing the culture from adult services B
- 22. Language and vocabulary (takes a long time to be approved by trust and by that time it's out of date) leaflets sometimes not sure if useful for YP but not all YP can access on line. B
- 23. Money money money, overspecialisation, non-traditional working times not always attractive, poor conceptualisation of adolescent needs by managers and doctors B
- 24. A disregard for early intervention from the top down. B
- 25. Barriers structural –between paediatric and adult services e.g. obesity,cardiovascular health, stress, long term benefits. Winning arguments and data savings social care support health, separate work B
- 26. Perceived money and costs, attitudes of health staff, young people are invisible in policy B
- 27. Organisational barriers B
- 28. Need a not one size fits all approach (F/B)

Question 6: What support or information do 21st century parents and professionals need to support 21st century adolescents...

- 1. Spaces are important, for accessing services. where what do these look like are they youth friendly. Links to confidentiality and consent.
- 2. Youth workers in hospital settings
- 3. Confidentiality is key, how to improve trust in health professionals, and allow to talk when goes wrong.
- 4. Need to consider different types of communication
- 5. Education
- 7. Sign posting, hubs, central resources
- 8. Better understanding of YP, teen children good but harking back to own experiences not necessarily relevant, tutorials from YP on e.g. Facebook or Snapchat(communication), continual education from YP to medical profession, feedback from YP constant but constraints of acting within NHS rules.
- 9. Ready steady go, education about what e-tech kids are using, support for parents let go, signposting
- 10. Effective signposting
- 11. Peer support parents support, ethics of introducing to each other.
- 12. Recognising mental health issues in young people with long term conditions, training for parents/carers, signposting, normal living "being healthy"

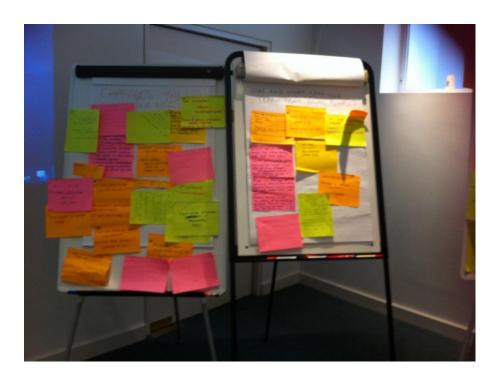
#### Other:

Need places in hospital for young people

### Photographs taken throughout the day







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