

Transition of Care Review

Experiences of those moving from children's to adults'
health and care services – Feb 2023

services and *“support smoother transition”*. This would give patients *“access to named persons in specialities for advice/support”*

Some respondents told us they felt that things could be improved by *“Identifying patients earlier”* and *“Starting the process earlier”*. Others told us that they would like to see *“Stronger links”* between children’s and adults’ teams, and that an increased *“overlap between services”* and use of *“assessment tools”* would help provide a *“greater understanding of patients needs”*.

Other comments from professionals included:

- *“better relations between children's and adults teams and knowledge of what they all do so we can support families”*
- *“Realistic expectations being set. Signposting to self-management, personal health budgets”*
- *“Perhaps meetings for parents to prepare for transition - often they feel worried”*

“In my opinion adult services need to appreciate that these young people are living longer and so transition from children's services whereas historically this has not been the case. Adult services needs rapid development in order to meet the needs of this patient group and ensure consistency of care is provided.”

For those we interviewed we heard that, having the single point of contact that you get in children’s services was highlighted by young people and families/carers as one of the most positive parts of the service and process. We heard from one children’s service professional that young people and families *“get really nervous”* approaching transition age because they *“don’t want to lose that support”*, however in many cases they are simply *“the number in the phone or on the fridge”*. The professional on the adult side of this service also told us that they provide leaflets with the team’s pictures and contact so that young people and their families/carers don’t lose the comfort of knowing there is someone *“at the end of a line or the end of an email.”*

Another improvement that a parent felt there could be, was involving parents more in some of the transitions and planning meetings. Concerning their experiences with health services, they told us that they thought *“they relied very much”* on the input of their young person and not *“enough opportunity for parents to have a say”* or *“raise their concerns”*. They also felt that by not being

involved that the professionals may not be *"getting the whole picture"* which they felt could impact treatment decisions.

We also asked public and professionals where they felt the biggest gaps in support were and if there were any improvements they could think of that would make experiences of transitioning better.

A common theme that emerged from both public and professional interviews was that there is a gap in support for the 18 to 30 age range, with one parent telling us that they thought *"young people are too young, then, to be ditched at 18 as well."* and that is *"is quite a vulnerable time"* in life for young people. What they would like to see is a point of contact for young people or parents/carers to be able to speak to and get support from, *"You just want someone to ring and get advice"*, particularly for the young people as they feel they need someone who is not a parent to talk to.

"it's just having someone to go to for some advice when you are having a difficult day."

Professionals felt there could be improvements made in the handover process. They told us that they felt a *"more multidisciplinary transition appointment"* would be appropriate as in many cases the young people transitioning have more conditions/complex needs. This would also allow any fears and concerns to be relayed mean that *"parents know who each of the professionals are that their young person is going to transition on to."*

We also spoke with one professional, working with supporting children with life-limiting illness, who told us they found that the paperwork involved in the process was *"quite complicated"* and can be *"quite daunting"* for families and felt that *"it could be broken down easier"* so as not to overwhelm the families.

Advice

Finally we asked both public and professional interviewees if they had any advice they would give to someone going through, or about to go through, the transition process.

The biggest piece of advice that both public and professionals gave was to 'ask questions' and 'get all the information you can'. One parents' advice was: *"ask*

lots of questions. Stick to your guns. If you think you're not getting the support that's needed, you have to say it. But don't be aggressive, just be polite".

"There's no such thing as a silly question. And the luxury of the transition appointments is time."

Other advice was to start looking into the process as early as is possible and stay on top of things during the process. One professional said "*start as early as possible*" because they think time is needed to gather information and work towards adult services.

A final piece of advice from a professional was "*Not to panic*", because the process can be daunting and confusing so be sure to ask questions and raise any concerns.

What this means

There are around 123,000 students in primary and secondary education in Norfolk (Flourish, 2021) and the population of 18 year olds in Norfolk is approximately 9,000 (Norfolk Insight, 2023). The number of young people with complex health needs who receive Special Education Needs (SEN) support or Education, Health and Care Plans (EHCPs) is around 20,800 (Flourish, 2021). Therefore the responses in this report are a small sample in relation to all those in Norfolk who are transitioning. However, there are some consistent themes in the experiences of those who have given their feedback and that has enabled us to identify areas for potential improvement.

Whilst the focus of this work was on the transition from children's to adults' services, through our engagement we received positive feedback about children's services. From the responses we received the transition process for many services in Norfolk could be greatly improved in terms of consistency, communication, and support in the overlap (young people aged 18-25).

There is a variation in the levels of support experienced, during and after the transition process, depending on the services being accessed. The services that received more positive feedback included GPs, community nurses, nephrology, physio, and OTs. We received more neutral or negative feedback for mental health services as well as some learning disability services. In some cases it was reported that there was "drop-off" in support provision, which was acknowledged by some of the professionals we spoke with. Ensuring the consistency of support during transition for all services could improve health outcomes for young people, particularly those with complex health needs transitioning multiple services.

We know that access to appropriate mental health support is important for increasing the prospects for healthy and happy lives for children and young people (NHS, 2023). From our previous report on community based mental health services for adults (which can be found here:

<https://healthwatchnorfolk.co.uk/report/community-based-mental-health-services-in-norfolk-and-waveney-year-one-report/>), we found that patients experienced issues and gaps when accessing services. Investigating which

services experience this 'gap' through patient feedback, and addressing the issue by making sure young people can still access appropriate levels of support until they are fully adopted by adult services will be key to improving wellbeing. We would like to see the introduction of additional support for 18 – 25 year olds in the form of service helplines and key points of contact to help ease the transition process, manage the gap/drop-off in support, and lead to improvements in health outcomes.

In terms of the professionals' experiences of supporting young people and their families/carers through the transition process, there was a very mixed response. Some told us that the experience overall had been positive and that they worked closely with their service counterparts and the families to ensure that relevant people had the information they needed and that the process went as smoothly as possible. Professionals also told us that the process varied depending on specialism and what support was available on the adult side of the process, not only this but patient experience could vary further in more complex cases where those with complex health needs are likely to be transitioning to multiple services/specialisms.

Poor communication was a theme across many services and there is a mismatch between the views of professionals and parents/carers concerning communication. It is apparent that services could do more to improve lines of communication during the transition process. The keyworker services, on the children's side, were praised for giving young people and their families/carers a point of contact and someone to communicate with them through the process. We would like to see the introduction of a similar function/role in the adult services. This would be beneficial to help keep the lines of communication strong, and would be particularly useful for those with complex needs who are likely to be accessing multiple services.

There was also a mismatch between professionals' feedback that they provide information and young people and families stating that they didn't receive information. It is difficult to know why there is a difference; it could mean that, for some, the information being given is not clear and so the perception of the young people and their families/carers is that they haven't received any information to support the process. There would appear to be a lack of understanding in what patients and families need in terms of information, which in turn results in more confusion and lack of understanding from the young people and their families/carers.

Reviewing the information provided by both children's and adults' services to ensure that this is lined-up and that adequate information is being provided by all services involved would help to improve consistency and support a smoother process. Consulting patients and families through feedback surveys/forms would help to review the clarity of the information and ensure that it is communicated well and could also help in alleviating some of the worries and concerns young people and their families have about the transition process.

The involvement of parents/carers is variable; with some parents feeling that they were excluded from the process and others who felt that the key to the success of the transition was the work they had undertaken to make things happen. Finding suitable ways in which parents/carers can be involved in the process without impacting on the independence of the young person is important and we would like to see more consideration for the involvement and support of parents and carers through this difficult period.

There are issues with the planning for young people to move from children's to adult services. Regardless of involvement in the creation of plans, issues that were raised included poor execution and support for plans, and poor communication of complicated paperwork. It would be beneficial to look into further ways care plans can be communicated, broken down, and made more understandable for young people and their families. Not only this, but supporting them with understanding how their plan will change over time and during the transition to make this less daunting. This can also link in with potential on-going keyworker support, giving young people the opportunity to contact someone when they have concerns or are unsure on the details of an updated plan. Additionally, looking to line-up systems (e.g., using the shared care record) could aid with managing care plans and making it so young people and their families/carers don't feel as if they have to retell their story for each new adult service.

Recommendations

From the findings of this piece of work several recommendations can be made for Norfolk Community Health and Care NHS Trust (NCH&C), and for the other services (Such as GPs, hospital departments, and adult mental health services) helping young people through the transition process, to consider regarding improving young people's, and their families/carers, experience of transitioning from children's to adults' health and care services.

1. Gather feedback – Establish processes for gathering feedback from young people and families/carers. This will enable a better understanding of what is needed by patients and families, and which services are managing the process well and which need improvements. This will also identify barriers to successful transition.
2. Improve communication – Communication with young people and their families could be improved to show what to expect from the transition process and how the adult services differ from children's. Improve communication between professionals to ensure better join-up of services and smooth transition.
3. Point of contact/Keyworker – Consideration should be given to appointing a keyworker who is responsible for supporting the young person and their family through the process, acting as a consistent point of contact during transition for both children's and adults' services. This could include specialist transition support for those aged 18-25 ensuring a smooth transition and reduce the risk of drop-off in support provision.
4. Planning process – Review the planning process for all services so that all are able to access records and minimise the need for patients and families to 're-tell their story'. Include aspects for parents/carers to ensure they have knowledge on how they can best support their young person.
5. Involvement of parents/carers – Actively encourage parents and carers to be involved in the planning for transition, as they can help the young person move toward independence in managing their care.

We acknowledge that the sample size for this work was small, however, within this there was considerable feedback concerning transitioning between child and adult mental health services. From our ongoing work evaluating the Community Mental Health Transformation we are aware of the plans to

transform these services in Norfolk and Waveney. As the NHS Long Term Plan includes a new approach to young adult mental health to support transition (NHS, 2019), we hope that the Community Mental Health Transformation includes plans to improve the support for young people transitioning from Children's mental health services.

Formal Response

We received an official response to this report and the recommendations from Helen Bradley, Quality Matron for Mill Lodge and Children's Services, on behalf of Norfolk Community Health & Care.



How NCHC will respond to recommendations:

There is a national and local drive to develop and improve on the Transition experience for young people and their families. We acknowledge NCH&C are part of a system-wide approach to work alongside our partners in healthcare provision to improve these experiences and develop our services, so they meet the needs of local young people. As a result of these findings, we will commit to:

- Developing a Children and Young People's forum. This will provide a platform for capturing the experiences and opinions of local children and young people who use our services. "Young Voices Together" was launched at NCH&C in June 2023.
- Target those young people and their families who have recently gone through the transition process with the Friends & Family test to capture their feedback of their experiences.
- Share the report with NCH&C's Child to Adult Transition group and across NCHC services to support internal awareness and learning.
- Share the report with the Integrated Care Board and partner agencies to support systemwide ownership of the findings and commitment to improvement. (Note: the ICB helped in the development of the survey questions).
- Develop a NCH&C transition leaflet (with Easy read version) aimed at young people and their families to support them with the transition process
- Develop a NCH&C policy on Transition to support Trust wide standards of care around transition for both Children's and Adult services. (Completed June 2023).
- Develop individual NCH&C services' responses to transition, working with partner agencies to promote approved processes and plans of care.
- Adopting the role of "named clinician" for transition across NCH&C's Children's services.
- Raising awareness and engaging with adult services to be more involved and accountable in the transition process.
- Consider the introduction of a post-discharge contact in NCH&C's Children's services following transition, to follow up and ensure the process is working as it should.
- Extend the roll out of the Carer's passport for parent/carers as their child enters the transition process, which will then support their continued involvement. Ensure families have information around Mental Capacity Act and the role of Power of Attorney.

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Appendix

Appendix 1: Public Interview Guide



Transitions Interviews – Public

Introductions

Confirm participant is happy for interview to be recorded for transcription purposes.

Inform that recordings will be deleted once the write up is complete and any direct quotes will be anonymised.

Who we are:

'Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge. Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more. We also give out information about the health and care services available in Norfolk and direct people to someone who can help.'

The Project and purpose of interview:

We are working with the Norfolk Community Health & Care NHS Trust (NCH&C) to explore the views and experiences of how young people (and their families) have experienced the move between children's and adult's health and care services.

We want to spend some time speaking to a small group of young people and/or their families in Norfolk.

For the purposes of the interview, you should have recent experience (in the last 12 months) of transitioning from children's health and care services to adult's health and care services.

We want to hear what it has been like accessing services yourself and/or for the person you care for.

We'd like to hear what has been positive and where you would like to see improvements or changes.

There are no right or wrong answers we are just really interested in hearing peoples' personal experiences and opinions.

The information we take away from the interview will be anonymised and will be used in a report to be given to NCH&C so they can find out what is working well and what needs improvement.

Questions/Prompts:

Could you tell us your role (parent, carer, etc).

Which service and departments were you/they accessing and which are they moving to?

If you feel comfortable doing so could you give some background for context?

Please tell us about your/the person you care for's experience of moving from Children's services to Adults' services.

Prompt: Was there anywhere that you looked for and where did you find support? (e.g. the services, charities, or friends/family)

Prompt: Do you feel that you were involved and listened to during the process/planning? Did you have a point of contact? And how was information communicated to you?

Prompt: What have you found to be different between the children's and adults' services? Is there anything you feel that is missing?

Prompt: Was there anything that was done particularly well/any positives you want to highlight?

Prompt: What would have made the experience better? (or even better if experience was good) Is there anything in particular that you felt could be improved upon?

Finally is there any advice that you would like to give for others who will be going through this move in the future?

Thank you

Thank you for your time and taking part by telling us about your experience.

Appendix 2: Professional Interview Guide



Transitions Interviews – Professionals

Introductions

Confirm participant is happy for interview to be recorded for transcription purposes.

Inform that recordings will be deleted once the write up is complete and any direct quotes will be anonymised.

Who we are:

'Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge. Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more. We also give out information about the health and care services available in Norfolk and direct people to someone who can help.'

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We want to spend some time speaking to a small group of young people and/or their families in Norfolk.

For the purposes of the interview, you should have recent experience (in the last 12 months) of transitioning from children's health and care services to adult's health and care services.

We want to hear what it has been like accessing services yourself and/or for the person you care for.

We'd like to hear what has been positive and where you would like to see improvements or changes.

There are no right or wrong answers we are just really interested in hearing peoples' personal experiences and opinions.

The information we take away from the interview will be anonymised and will be used in a report to be given to NCH&C so they can find out what is working well and what needs improvement.

Questions/Prompts:

Could you tell us your organisation & role

Which services and departments do you typically see/help young people access and which do they moving to?

Please tell us about your experience of young people moving from Children's services to Adults' services. Are there any specific examples you would like to highlight/share?

Prompt: What kind of support do you offer for young people and their families during the move from children's to adults' services?

Prompt: What have you found to be different between the children's and adults' services? Is there anything you feel that is missing?

Prompt: Is there anything that is done particularly well/any positives you want to highlight?

Prompt: Is there anything that you think would make patient experiences better? Is there anything in particular that feel could be improved upon?

Finally is there any advice that you would like to give to patients who will be experiencing this move?

Thank you

Thank you for your time and taking part by telling us about your experience.

Appendix 3: Public Survey



Transitioning Services - Public Survey

Transition from children's to adults' health and care services

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge.

What is this survey about?

Healthwatch Norfolk are working with the Norfolk Community Health & Care NHS Trust (NCH&C) to explore the views and experiences of how young people (and their families) have experienced the move between children's and adults' health and care services.

If you have recent experience (in the last 12 months) of moving between children's and adults' health and care services we would like to hear your views.

How the survey results will be used

Anonymised survey data will be shared with NCH&C to enable them to share good practice and assess areas for improvement in the transition from children's to adults' health and care services. Healthwatch Norfolk will not disclose any confidential information unless there is a genuine and urgent concern for an individual's safety or wellbeing.

The survey results will also be used by Healthwatch Norfolk to make recommendations to service providers as part of our evaluation report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:

www.healthwatchnorfolk.co.uk/about-us/privacy-statement

If you would prefer to do this survey with us over the phone, please call Healthwatch Norfolk on 01953 856029 and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Survey Closing date: 6th January 2023

Please tick to confirm *

I have read and understood the above statement

Healthwatch Norfolk produce newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

If you have recent experience (in the last 12 months) of moving between children's and adults' health and care services please answer the questions below to the best of your ability.

1. Please check which applies to you:

- I am the person who has experienced moving from Children's to Adults' services
- I am the family member of someone who has moved/is moving from Children's to Adults' services
- I am the carer of someone who has moved/is moving from Children's to Adults' services
- Other (please specify):

2. How old are you/ is the person experiencing the transition to adult services?

3. Please tell us which service(s) your experience relates to:

4. How would you rate the overall experience of transitioning from children's to adults' services?

- Very Good
- Good
- Ok
- Poor
- Very Poor
- Not sure
- Not Applicable

5. Were you given any information and support in preparation for the move from children's to adults' services?

- Yes
- No

If yes, please provide details:

6. Did you have any worries or concerns about moving from children's to adults' services?

Yes

No

If Yes: What were they? Did you raise them at the time? And were they addressed?

7. Who has been involved in the move/ transition from Children's to Adults' services? (e.g., consultants, GPs, parent and/or carers)

8. Did you feel involved in your transition plan?

Yes

No

Please tell us why:

9. Do you feel you were given the skills to attend appointments independently?

Yes

No

Please tell us why:

10. Overall, how would you rate the communication from the services during the transition process?

Very Good

Good

Ok

Poor

Very Poor

Not Sure

Not Applicable

11. How would you rate the consistency of the care from the services?

- Very Good
- Good
- Ok
- Poor
- Very Poor
- Not Sure
- Not Applicable

12. Please tell us about your experience of transitioning from Children's to Adults' services. Tell us about your journey:

(E.g. What worked well and what do you feel could be improved?)

13. Is there anything else you would like to share with us regarding the transition from Children's to Adults' services?

14. If you would be happy for us to contact you to speak about your experiences in more detail please provide your name and preferred contact information below:

If not please check here

4. Demographics

In this next section we will be asking you some questions about yourself and your life. Your answers help us make sure that we engage with people from different backgrounds and that we understand the needs of different groups in our community. Remember: all your answers are strictly confidential and the survey is anonymous.

15. How old are you?

16. What is your gender?

- Male
- Female
- Non-binary
- Genderfluid
- Genderqueer
- Intersex
- Prefer not to say
- Prefer to self-describe:

17. What is the first half of your postcode?

18. What is your ethnic group?

- Arab

Asian / Asian British:

- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian / Asian British background

Black / Black British:

- African
- Caribbean
- Any other Black / Black British background

Mixed / Multiple ethnic groups:

- Asian and White
- Black African and White
- Black Caribbean and White
- Any other Mixed / Multiple ethnic groups background

White:

- British / English / Northern Irish / Scottish / Welsh
- Irish
- Gypsy, Traveller or Irish Traveller
- Roma

Any other White background

Other:

Any other Ethnic Group

Prefer not to say

If other, please specify:

19. Do you consider yourself to have a disability?

Yes

No

I'd rather not say

20. Where did you hear about this survey?

GP website

Healthwatch Norfolk Event

Healthwatch Norfolk Newsletter

Healthwatch Norfolk Website

News (website / radio / local newspaper)

Search Engine (e.g. Google)

Social Media (e.g. Facebook / Instagram / Twitter)

Through a friend or co-worker

YouTube

Other (please specify):

Appendix 4: Professional Survey



Transitioning Services - Survey for Staff/Professionals

Transition from children's to adults' health and care services

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge.

What is this survey about?

Healthwatch Norfolk are working with the Norfolk Community Health & Care NHS Trust (NCH&C) to explore the views and experiences of how young people (and their families) have experienced the move between children's and adults' health and care services.

If you work in health and social care and have experiences of supporting young people transitioning from Children's to Adults' services, we would like to hear from you.

How the survey results will be used

Anonymised survey data will be shared with NCH&C to enable them to share good practice and assess areas for improvement in the transition from children's to adults' health and care services.

The survey results will also be used by Healthwatch Norfolk to make recommendations to service providers as part of our evaluation report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:

www.healthwatchnorfolk.co.uk/about-us/privacy-statement

If you would prefer to do this survey with us over the phone, please call Healthwatch Norfolk on 01953 856029 and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Survey Closing date: 6th January 2023

Please tick to confirm *

I have read and understood the above statement

Healthwatch Norfolk produce newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

1. Please tell us which organisation/ specialty you work in:

2. How would you rate the overall process of transitioning from children's to adults' services in Norfolk?

- Very Good
- Good
- Ok
- Poor
- Very Poor
- Not sure
- Not Applicable

Please use this space to tell us why you have chosen this answer:

3. Do you provide information and support to patients and their families in preparation for the move from children's to adults' services?

- Yes
- No

If Yes: What information and support do you provide to patients and their families in preparation for the move from children's to adult's services?

4. Have patients expressed any worries or concerns about moving from children's to adults' services? If yes, what are they?

- Yes
- No

If yes, please provide details:

5. When transitioning a patient from children's to adults' services, how are they/ their family involved?

6. How is information shared from children's to adults' services and have you encountered any problems?

7. Overall, how would you rate the communication between clinician to patient/ family during the transition process?

- Very Good
- Good
- Ok
- Poor
- Very Poor
- Not Sure
- Not Applicable

Please use this space to tell us why you have chosen this answer:

8. Overall, how would you rate the communication between clinicians and organisations during the transition process?

- Very Good
- Good
- Ok
- Poor
- Very Poor
- Not sure
- Not Applicable

Please use this space to tell us why you have chosen this answer:

9. How would you rate the consistency of the care being provided?

- Very Good
- Good
- Ok
- Poor
- Very Poor
- Not Sure
- Not Applicable

Please use this space to tell us why you have chosen this answer:

10. What do you think works well with the current transitioning support?

11. What would you like to see change and how can the experience be made better for patients? (e.g., starting the process earlier)

12. Is there anything else you would like to share with us regarding the transition from Children's to Adults' Services?

13. If you would be happy for us to contact you to speak about your experiences in more detail please provide your name and preferred contact information below:

If no please check here

4. Demographics

In this next section we will be asking you some questions about yourself and your life. Your answers help us make sure that we engage with people from different backgrounds and that we understand the

needs of different groups in our community. Remember: all your answers are strictly confidential and the survey is anonymous.

14. How old are you?

15. What is your gender?

- Male
- Female
- Non-binary
- Genderfluid
- Genderqueer
- Intersex
- Prefer not to say
- Prefer to self-describe:

16. What is the first half of your postcode?

17. What is your ethnic group?

- Arab

Asian / Asian British:

- Bangladeshi
- Chinese
- Indian
- Pakistani
- Any other Asian / Asian British background

Black / Black British:

- African
- Caribbean
- Any other Black / Black British background

Mixed / Multiple ethnic groups:

- Asian and White
- Black African and White
- Black Caribbean and White

Any other Mixed / Multiple ethnic groups background

White:

British / English / Northern Irish / Scottish / Welsh

Irish

Gypsy, Traveller or Irish Traveller

Roma

Any other White background

Other:

Any other Ethnic Group

Prefer not to say

If other, please specify:

18. Do you consider yourself to have a disability?

Yes

No

I'd rather not say

19. Where did you hear about this survey?

GP website

Healthwatch Norfolk Event

Healthwatch Norfolk Newsletter

Healthwatch Norfolk Website

News (website / radio / local newspaper)

Search Engine (e.g. Google)

Social Media (e.g. Facebook / Instagram / Twitter)

Through a friend or co-worker

YouTube

Other (please specify):

Appendix 5: Demographics

N.B.: For some of the responses we received, individuals identified themselves as parents/carers of young people but provided their young persons age in their answers to the demographic questions.

		Percentage of Public respondents (n=34)	Number of Public respondents (n=34)	Percentage of Professional respondents (n=17)	Number of Professional respondents (n=17)
Age	16 to 25	44%	15	6%	1
	26 to 35	3%	1	18%	3
	36 to 45	9%	3	29%	5
	46 to 55	29%	10	24%	4
	56 to 65	9%	3	18%	3
Gender	Male	24%	8	24%	4
	Female	76%	25	76%	13
Ethnic Group	Any other Black / Black British background	3%	1	0%	0
	British / English / Northern Irish / Scottish / Welsh	91%	29	100%	16
	Any other White background	3%	1	0%	0
	Prefer not to say	3%	1	0%	0

Do you consider yourself to have a disability?	Yes	48%	16	12%	2
	No	48%	16	88%	15
	I'd rather not say	3%	1	0%	0

Appendix 6: List of Services

The services that respondents told us their experiences related to, included:

- General Practice (GP) Services
- General Adult Services
- General Children's Services (Paediatrics)
- Child Social Services
- A&E and Hospital Inpatients
- Nephrology
- Child and Adolescent/Children and Young People's Mental Health Services (CAHMS/CYPMHS)
- Adult Mental Health Services
- Haematology and Oncology
- Preparing for Adult Life (PfAL)
- Starfish Plus to Adult Learning Disabilities
- Epilepsy Clinics
- Children with Disabilities to Continuing Health Care (CWD to CHC)
- Day Support
- Autism Services
- ADHD Services
- Gastroenterology
- Asthma
- Physio
- Occupational Therapy
- Dieticians
- Consultants
- Community Nurses
- Diabetes Services

Areas covered by the professionals we heard from included:

- Neurodevelopmental services
- Children's/ Paediatric Occupational Therapy
- Epilepsy
- Learning Disabilities
- Palliative Care



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