

Engagement Report: Black Country Transforming Care Programme

June 2019

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1. Executive Summary

Introduction

Following the investigation into abuse at Winterbourne View in 2015 and other similar hospitals, there has been a cross-government commitment to move all people with learning disabilities who were inappropriately placed in such institutions into community care. To achieve reduced hospital admissions and shorter in patient stay more people need to be supported to receive health assessment and treatment in the community and close to home wherever this is possible.

The Black Country Transforming Care Partnership (BCTCP) has been working with people with learning disabilities, their families and carers to develop and deliver a new community model of care that maintains their rights, respect and dignity. This work has been informed by feedback from previous engagement undertaken by BCTCP between April 2016 and July 2018.

The new proposed model of care means investment is in a community model and, as a result, fewer assessment and treatment beds will be needed. Clinicians and other experts have analysed the existing assessment and treatment units and believe the unit that best meets the requirements for a safe and effective service is Penrose House in Sandwell.

An engagement exercise was undertaken by the CCGs from Thursday 21 March to Thursday 23 May 2019.

The purpose of the engagement process undertaken was to seek the views of stakeholders, service users, carers and family members on the following:

- The introduction of a new community model for people with learning disabilities that provides enhanced support in the community.
- The permanent closure of specialist inpatient beds at Ridge Hill Hospital, Dudley and Orchard Hills/Daisy Bank, Walsall. (These are beds that are reserved for assessing and treating people with learning disabilities and are not connected to general hospital services).

1.1 Engagement process

- The CCGs managed all stakeholder engagement across the Black Country and West Birmingham.
- **Dudley Voices for Choices (DVC)** is an advocacy group for people who have a learning disability or autism. DVC is a member of the TCP programme board to ensure that people with learning disabilities are represented at programme level.

- The CCGs commissioned NHS Arden and GEM CSU to support the engagement by: producing an engagement document to promote understanding of the TCP programme and the proposed new model; producing a questionnaire to allow feedback (see appendix A); to advise on the format of the stakeholder events and to capture all feedback at those events.
- As DVC supports people with learning disabilities and autism to speak up for themselves, they were also commissioned to undertake outreach engagement in the community and produce an easy read version of the engagement document and questionnaire (see appendix B).
- Arden and GEM were also commissioned to analyse all feedback from the engagement process and to produce this engagement report.
- Several thousand stakeholders were contacted by the CCGs and invited to get involved by attending one of the four stakeholder events and/or completing the online questionnaire.
- **Four stakeholder events** (one in each of the Black Country and West Birmingham CCG areas) took place to explain the TCP programme and hear views on the proposed service model. All feedback from the stakeholder events has been collated in this report.
- **Outreach engagement** with service users, their carers and families was undertaken by DVC; 174 conversations took place. DVC undertook interviews across Sandwell, Wolverhampton, Walsall and Dudley.
- A press release and social media also informed people how to get involved by attending one of the four stakeholder events and/or completing the questionnaire.
- Information was published on the CCG websites.

1.2 Key themes from the stakeholder events included:

- Positivity for the community focus offered by the new model.
- The importance of relationship building and maintaining good relationships between, patients, family members, carers and professionals.
- Transport and access to the Penrose site for visitors.
- Consideration for those with autism.
- Consideration for those in transition (aged 16 to 18 years old).
- The response to crisis.
- The number of treatment and assessment beds (10) in the new model.

1.3 Key themes from the outreach engagement included:

- Transport and access to the assessment and treatment centres.
- Cost implications of travelling around the areas.

- Enough beds to meet the needs of all areas.

1.4 Questionnaire analysis (50 surveys completed)

- Most respondents (62%) felt it would have a positive impact if care and support were delivered in the community rather than in a hospital, compared to 10% of respondents who said it would have a negative impact.
- Nearly half of respondents (46%) felt it would have a positive impact if care and support were delivered in the community for a person with a learning disability and/or autism displaying challenging behaviours, compared to just over a quarter (28%) who believed this would have a negative impact.
- Many more family members and carers (44%) felt it would have a positive impact if care and support were delivered in the community, than felt it would have a negative impact (14%).
- When asked: 'If the assessment and treatment centre was based at Penrose House what would the impact be for you?', 28% of respondents felt it would have a negative impact; 22% believed this would have a positive impact. Other responses (36%) included: 14 respondents were not sure; three believed the distance to be an issue; one preferred not to answer this question.
- When families and carers were asked about the impact of having the assessment and treatment centre based at Penrose House, 20.41% felt this would have a negative impact; 18.37% believed the impact would be positive. The largest number of respondents (51.02%) were unsure; 10.20% believe this would have no impact.
- People were asked how important help/support and information and advice were across a range of circumstances. These included: personal support; environments; family carer support; information and advice, for all areas most people selected 'very important' as their answer.
- People answered questions on prevention of crisis admission to hospital. Categories included: support with daily activities; communication; understanding situations that may lead to challenging behaviour and avoidance; personal support; environment; family/care support and information and advice. For all answers most people said it was 'very important' to have support across all categories to prevent crisis.
- People were asked questions on support needed for discharge to prevent readmission. A range of categories were considered: support with daily life; communication; behaviour; personal support; environment; family/carer support and information and advice. Most respondents felt that support for all categories was very important.
- When asked what respondents felt stopped or delayed a person getting the right support in the community areas, responses included:
 - Lack of family support and affordable care homes

- Lack of funding for services
- Lack of communication between the different services and professionals.
- The need for accurate and up to date information about services
- The need for more qualified staff.
- People were asked to consider their experience of things going wrong with being supported/supporting someone in the community. Responses included:
 - Lack of information for patients being discharged from hospital
 - Lack of support when carers are sick
 - The right support may not be offered
 - Lack of communication and not planning for end of life care which can result in unnecessary hospital admissions
 - Not having appropriate funding in place to support patients.

1.5 Summary of findings and recommendations (please see in full at the end of the evaluation report)

1.5.1 Key themes

- Positivity about the community focus offered by the new model.
- The importance of relationship building and maintaining a good relationship between patients, family members, carers and professionals.
- Transport and access to the Penrose site for visitors.
- Consideration for those with autism.
- Consideration for those in transition (age 16 to 18yrs).
- The response to crisis.
- The number of beds (10) in the new model.
- Concerns about not having enough staff.

1.5.2 Recommendations

To consider all feedback from the engagement process recorded in this report and appendices.

2. Introduction

Following the investigation into abuse at Winterbourne View in 2015 and other similar hospitals, there has been a cross-government commitment to move all people with learning disabilities who were inappropriately placed in such institutions into community care.

The NHS clinical commissioning groups across the country, in partnership with their local authorities, have been working to make improvements in care and support following the Winterbourne investigation.

The Transforming Care Programme was established to build on that work and accelerate progress to transform care and support for people with learning disabilities and/or autism. It is a nationally mandated programme that is being rolled out across the country.

In the Black Country and West Birmingham, the work in this area aims to:

- Improve quality of care for people with learning disabilities
- Improve quality of life for people with learning disabilities
- Enhance community capacity, thereby reducing inappropriate hospital admissions and length of stay.

Work so far has focused on areas such as:

- Early intervention to minimise the development of challenging behaviours
- Crisis prevention to provide the right kind of support to prevent and reduce instances of crisis
- Addressing crises by responding effectively to stabilise an individual's situation
- Ensuring effective discharge to avoid repeat hospital admissions.

The Black Country Transforming Care Programme is about making sure more people are supported to receive health assessment and treatment in the community and close to home wherever this is possible. Assessment and treatment will be provided by community teams with specially trained social workers, nurses, psychologists, psychiatrists and other staff. Service users will only go to hospital because their health needs cannot be met safely in the community at that time. Hospital care will be high quality specialist care and stays will be for the shortest time possible.

The Black Country Transforming Care Partnership (BCTCP) has been working with people with learning disabilities and their families and carers to develop and deliver a new community model of care that maintains their rights, respect and dignity. This work has been informed by feedback from previous engagement undertaken by BCTCP between April 2016 and July 2018. See table below.

Timeline	Activity
April 2016	Black Country Transforming Care Partnership (TCP) established to transform health and care services for people with learning disabilities and/or autism who may display behaviour that challenges
	Equality Impact Assessment of TCP Programme undertaken
	Engagement with carers. Commissioned by Sandwell and West Birmingham CCG and conducted by two independent members of the Care and Treatment Review Panel - six carers took part in half-day feedback session - Informal discussions with 10 people with learning disabilities, with or without autism, who had been discharged from hospital following a Care and Treatment Review
4 July 2016 to 22 August 2016	Public consultation in Wolverhampton on moving three assessment and treatment learning disability in-patient beds at Pond Lane Hospital to existing services in Dudley, Walsall and Sandwell
September 2017	Service user questionnaire – 133 questionnaires were completed by service users who were inpatients or at risk of admission, experts with lived experiences, carers, advocates and their support staff
January 2018 to July 2018	‘So, what next?’ engagement The ‘So what, what next’ Project was designed by the national Transforming Care empowerment steering group, a group of people with a learning disability and/or autism, or family carers, with lived experience of long stays in hospital settings. The project worked with 10 people within the Black Country with a learning disability with or without autism who had recently moved out of hospital, alongside the people who support them in the community.

The new proposed model of care prioritises investment in a community model designed to reduce the number of inpatient stays and ensure people with learning disabilities remain close to their communities, friends and families. As a result, fewer assessment and treatment beds will be needed. Clinicians and other experts have undertaken an options appraisal of the existing assessment and treatment units and believe the unit that best meets the requirements for a safe and effective service is Penrose House in Sandwell.

The purpose of the engagement process undertaken from Thursday 21 March to Thursday 23 May was to seek the views of stakeholders, service users, carers and family members on the following:

- The introduction of a new community model for people with learning disabilities that provides enhanced support in the community.
- The permanent closure of specialist inpatient beds at Ridge Hill Hospital, Dudley and Orchard Hills/Daisy Bank, Walsall. (These are beds that are reserved for assessing and treating people with learning disabilities and are not connected to general hospital services).
- The preferred clinical option to locate a single assessment and treatment centre at Penrose House, Sandwell.
- The impact (positive and negative) of proposed changes on service users, family members and carers and the support needed to be in place to make the new model successful.

3. Engagement Process

- The CCGs managed all stakeholder engagement across the Black Country and West Birmingham.
- **Dudley Voices for Choices (DVC)** are an advocacy group for people who have a learning disability or autism. The organisation is a member of the TCP programme board to ensure that people with learning disabilities are represented at programme level.
- As DVC support people with learning disabilities and autism to speak up for themselves, they were also commissioned to undertake outreach engagement in the community and produce an easy read version of the engagement document and questionnaire.
- The CCGs commissioned NHS Arden and GEM CSU to produce an engagement document to promote understanding of the TCP programme and the proposed new model, and a questionnaire to allow feedback. Both were available in hardcopy and online. Arden & GEM were asked to advise on the format of the stakeholder events and to capture all feedback at those events.
- The CSU was also commissioned to analyse all feedback from the engagement process and to produce this engagement report.
- Four stakeholder events took place to explain the transforming care programme and hear views on the proposed service model. All feedback from the stakeholder events has been collated in this report.
- Outreach engagement with service users, their carers and families was undertaken by local charity Dudley Voices for Choices; 174 conversations took place. Interviews were undertaken across Sandwell, Wolverhampton, Walsall and Dudley.
- Several thousand stakeholders were contacted by the CCGs and invited to get involved by attending one of the four stakeholder events and/or completing the online questionnaire.
- A press release and social media also informed people how to get involved by attending one of the four stakeholder events and/or completing the questionnaire.

3.1 Media

A press release was issued on 21 March 2019. There was no media uptake.

3.2 Websites

A dedicated webpage to publicise the consultation was launched on the CCG websites. Page views per CCG were as follows:

Sandwell and West Birmingham CCG webpage: 1,378 views

Wolverhampton CCG webpage: 1,520 views

3.3 Social media

Area	Tweets	Impressions	Retweets
Wolverhampton	30	12,507	34
Sandwell and West Birmingham	28	14,482	19
Walsall	5	5,916	10
Dudley	13	13,726	12
Black Country Partnership Foundation Trust (Black Country-wide)	3	2,195	1

4. Stakeholder Events

The CCGs and the Black Country Partnership Foundation Trust managed all stakeholder engagement. As part of the engagement process four stakeholder events took place across the Black Country and West Birmingham, in Walsall, Dudley, Sandwell and Wolverhampton. The purpose of the events was to explain the background to the Transforming Care Programme from a national and local perspective and to introduce the proposed model developed by the Black County Transforming Care Partnership (BCTCP). Stakeholders were in attendance to find out more and give their views. All feedback was recorded by Arden and GEM CSU.

Each of the stakeholder events followed the same format. In each area the lead CCG commissioner together with a clinician from the provider, presented the journey so far, from the national policy development to the local response. The proposed model for the delivery of TCP for adults with learning disabilities was explained and the following questions were posed to prompt small group discussions:

- What are the positive impacts of the proposed community model?
- Are there any negative impacts you would like to discuss?
- Is there anything else you would like to be taken into consideration?

After the workshop, key discussion points and questions were shared with all attendees. All questions were answered by a clinician or a commissioner from the TCP team. All feedback was collated for inclusion in this report.

Four stakeholder events across the Black Country and West Birmingham

4.1 Stakeholder Event in West Bromwich

Monday 8 April 2019, 1.30-3.30pm

This event was attended by 24 stakeholders from a range of organisations including: Options for Life, SAFS (Sandwell Asian Family Support Service), Sandwell MBC, West Minster School, El Marsh Care, Midway Care, Charnat Care, Careview Services, Sandwell & West Birmingham CCG (additional staff not delivering event). In addition, there were three members of the public, and a student of Wolverhampton University.

Feedback from the group discussions included:

Discussion point 1 - What are the positive impacts of the proposed community model?

- Accessibility

- Out of hours support
- Locality for Sandwell patients and families/carers will be easier
- Family benefits
- Fewer admissions/less time spent/my community
- Working together
- CTR's are key to positive outcomes
- Carefully thought through
- Great that public participation is taking place
- Intensive support site – great to have additional support in the community that you can access quickly
- Valuable to have clear pathway
- Consistency across all areas

Discussion point 2 – Are there any negative impacts you would like to discuss?

- Timeframes – changing delivery model takes time
- Journey time/locality for other areas
- Support for families to visit
- TCP for children – joint working with TCP for adults
- One attendee had a bad experience of treatment and assessment model
- May need an increase in social care hours
- There may be a negative impact on the carer if loved one gets better care. It is difficult for carers to let people move on

Discussion point 3 – Is there anything else you would like to be taken into consideration?

- Do families know what services are out there? Providers could communicate this with carers
- It's more than just a health issue – improved working together between health and social care
- Making sure people have knowledge of how TCPs will work together
- Information on stakeholder events
- Access needs to be prompt and responsive to crisis
- Approval for support service when in crisis
- More information, clearer about 10 beds
- Clear information on the offer of teams, that is updated
- Information for other providers on referral process for the enhanced community model
- Involvement – working together families/users
- Learning and evolution... no time limits

4.2 Stakeholder event in Wolverhampton

Tuesday 9 April 2019, 10am-12pm

Nine stakeholders attended the event from a range of organisations including the University of Wolverhampton, Dudley Voices for Choices, Beacon Vision and Mencap.

Feedback from the group discussions included:

Discussion point 1 – What are the positive impacts of the proposed community model?

- Quality of care
- Community integration
- Good move towards social model instead of medical model
- Bespoke for individual
- Improved efficiency
- No funding cuts/funds reallocated to community services
- Flexible staff movement
- Everyone has same level of care

Discussion point 2 – Are there any negative impacts you would like to discuss?

- Transport/travel to ATU in Sandwell
- Isolation due to ATU venue
- Support for families might not materialise

Discussion point 3 – Is there anything else you would like to be taken into consideration?

- Joint commissioning
- Strong user voice including family

The discussions led into a question and answer session, please see full details at Appendix C.

4.3 Stakeholder event in Walsall

Thursday 11 April; 4pm to 6pm

Fourteen stakeholders attended the event from a variety of organisations such as Healthwatch; Dudley Metropolitan Council; Walsall Council; Dignus Health Care; Care First Ltd and Dudley Voices for Choices.

Feedback from the group discussions included:

Positive Impacts:

- Better integrated working: it was felt that the new model would offer this opportunity but needed time and investment to make it work.
- Patients not having to go out of area was positive.
- Reducing beds was seen overall as positive. It was felt that having fewer beds would drive the community model and would be an impetus for more people to be supported in the community.
- Being supported in the community was felt to be more positive than having to be admitted to hospital unnecessarily for prolonged periods of time.
- Stakeholders saw the location of the proposed community model as positive due to the proximity of more facilities such as shops and community activities.
- Stakeholders felt that Penrose would become a hub of services and felt this was positive. In particular they welcomed the planned flexibility of the unit which would enable it to avoid issues around mixed gender accommodation.
- IST already based at Penrose will aid smooth transition.

Attendees did not express negative impacts but asked questions. For full details please see Appendix C.

Stakeholders also made the following points:

- The importance of working with partners such as the police service, the emergency services, and social care services, particularly to manage crisis situations. The importance of all personnel receiving training so that approach to crisis situations was consistent.
- Closer working together between health and social care across the area to meet patient needs was recommended.
- The importance of training and development for all staff working in the new model. The discussion point was made that if staff are working in both IST and AT4 legal boundaries need to be understood.
- The importance of patient centred services and the specialist support needed.
- Low need patients should be in mainstream services not specialist.
- There should be joint pathways with the mental health team.
- Currently, there are LD specialist nurses in Walsall for dementia and transition, it is important that these posts are maintained in the new model.
- It is important to consider how safeguarding responsibilities will be maintained in the new model e.g. Are the Safeguarding team at Sandwell ready for the impact of the new model?
- The importance of making and maintaining links to local community services. This will enable links to meaningful day opportunities. Community services available in the local area need to be scoped and relationships maintained.

- The importance of reablement skills development for service users.

4.4 Stakeholder event in Dudley

Thursday 2 May 2019, 5.30-7.30pm

Thirteen stakeholders attended the event from a range of organisations including: Dudley Heathwatch, PPGs, Dudley Voices for Choices, Camphill Village Trust, Riverside House. A student nurse also attended and members of the public.

Feedback from the group discussions included:

Positive Impacts:

- Individuals are being considered
- Penrose is well placed
- Transport is on a simple route
- Provides more opportunities to be independent
- Good discharge plans
- Winterbourne must never happen again. This model is the right direction.
- Right treatment, right place, shorter stay.

Attendees did not express negative impacts but asked questions. Please see questions and answers in full at Appendix C.

Attendees also made the following points:

- Autism should not be under mental health, it is neurological not mental health.
- Between the ages of 16 and 18, there is no support available. At 18, I can access adult services, but all young people should be supported with a transition plan (education and health plan), if you are not considered severe you don't get one. There is no access to mental health. There is a big gap in health services for 16- to 18-year-olds. The is needed before people get to crisis. Early intervention is needed. People need activity, purpose, opportunity. A lot has been cut and taken away and this leads to challenging behaviour due to frustration. There are not enough staff to provide the help needed, nurses have far too many patients.
- It is very important to understand that LD people can be very vulnerable in the community. People need to know how to look after themselves; for example, safe place schemes. There also needs to be more education to promote understanding among the community.
- Transport needs to be considered. It is important that access is easy so that relatives can visit.

- It is important that the length of stay in hospital is appropriate. Assessment and treatment centres should be no different than any other episode when you are treated for any other illness. The discharge date should be identified on day of admission.
- The environment and approach are so important. Well trained staff recognise triggers and crisis is prevented.
- The new model may lead to families having more responsibility and it is important not to overburden them. There is a need for relationship building between professionals and the family for some previous experience has made families reluctant to trust professionals. People need to understand what policies and processes are in place to ensure the patient's best interests are at the centre of decision making. carers and parents really know the patients.
- People are viewed in the community more as an individual and not as 'a patient'.
- A de-escalation suite should be considered as part of the new model
- It is important to have access to other services.

4.5 Key themes from all stakeholder events

Across all engagement events the community focus of the new model was received with positivity. Any concerns were shared and discussed, and questions answered. Key themes emerged across all stakeholder events, such as:

Key themes

- The community focus offered by the new model.
- The importance of relationship building and maintaining good relationships between, patients, family members, carers and professionals.
- Transport and access to the Penrose site for visitors.
- Consideration for those with autism.
- Consideration for those in transition (aged 16-18).
- The response to crisis.
- The number of beds (10) in the new model

5. Outreach Engagement

The charity, Dudley Voices for Choices was commissioned by the CCGs to undertake face to face, targeted engagement with potential service users, service users, family members and carers across the Black Country and West Birmingham as part of the Transforming Care Programme engagement process. During the outreach engagement people were encouraged to complete the easy read version of the questionnaire.

- 174 conversations took place.
- Interviews were undertaken across Sandwell, Wolverhampton, Walsall and Dudley.
- 11 community groups were engaged with and 184 easy read questionnaires distributed across the Black Country and West Birmingham.
- Wherever possible, the easy read version of the questionnaire was completed face-to-face. However, due to the complexity of the subject matter for some people with learning disabilities, feedback was limited.
- 39 easy read questionnaires were completed, some fully, some to a limited extent. Please see the findings from the questionnaire feedback in section 5.
- Carers, and family members were also invited to complete the questionnaire.

5.1 Key themes from the 174 conversations

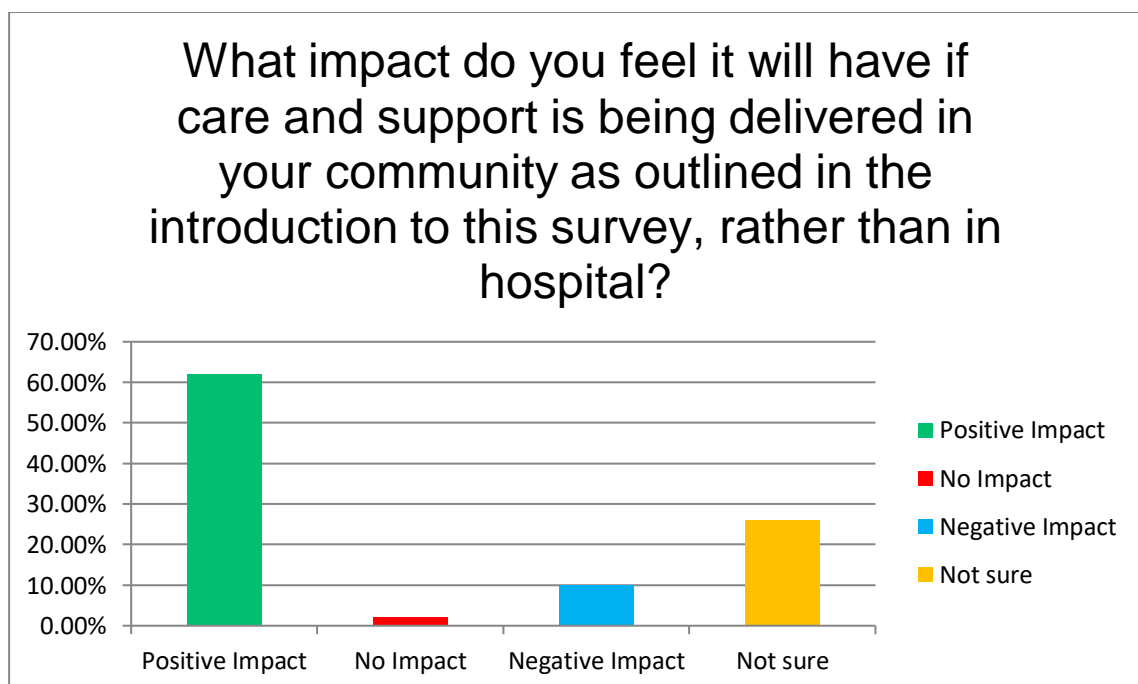
- Transport and access to the assessment and treatment centres.
- Cost implications of travelling around the areas.
- Having enough beds to meet the needs of all areas.

6. Questionnaire Analysis

Responses received are from all four areas and have not been separated due to small numbers and no notable differences in views were presented.

1. What impact do you feel it will have if care and support is being delivered in your community as outlined in the introduction to this survey, rather than in hospital?

Answer Choices	Responses	
Positive Impact	62.00%	31
No Impact	2.00%	1
Negative Impact	10.00%	5
Not sure	26.00%	13
	Answered	50
	Skipped	0

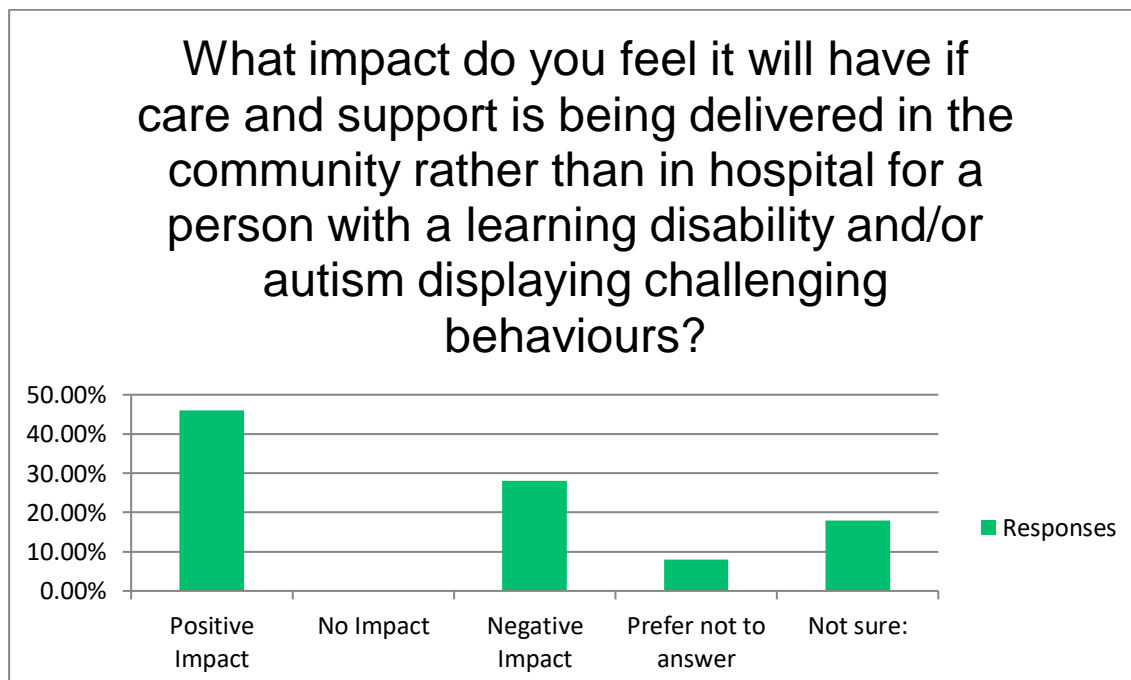


The majority of respondents (62%) felt it would have a positive impact if care and support was delivered in the community rather than in a hospital, this was compared to 10%

stating it would have a negative impact. A further 2% felt this would have no impact and 26% were unsure.

2. What impact do you feel it will have if care and support is being delivered in the community rather than in hospital for a person with a learning disability and/or autism displaying challenging behaviours?

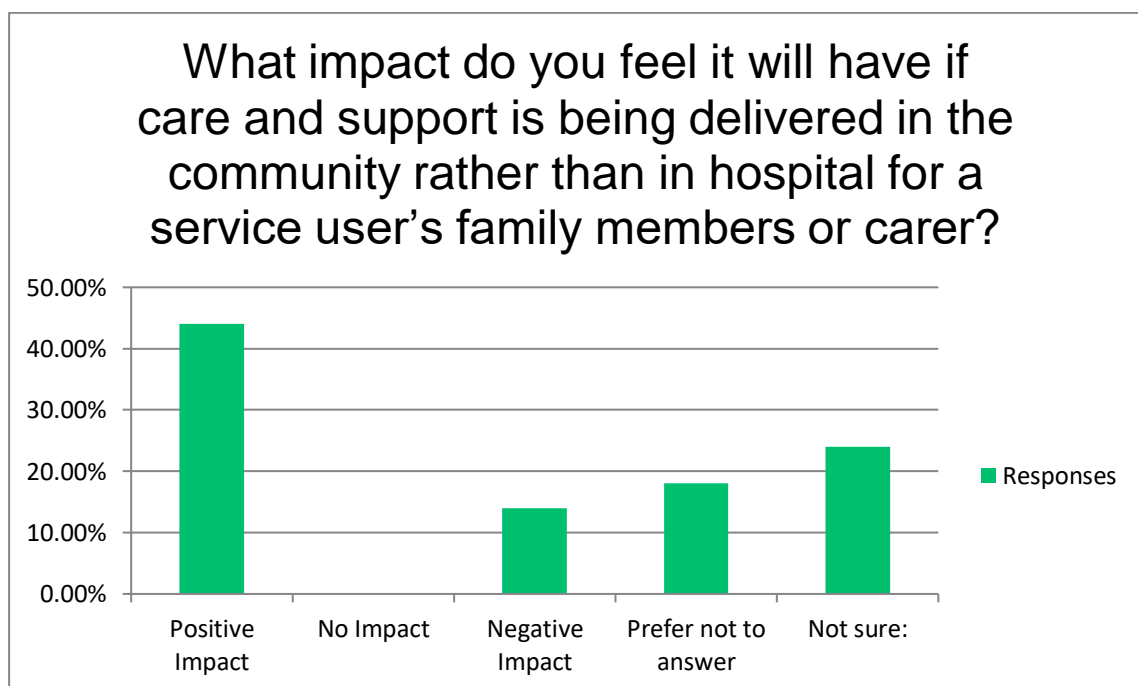
Answer Choices	Responses	
Positive Impact	46.00%	23
No Impact	0.00%	0
Negative Impact	28.00%	14
Prefer not to answer	8.00%	4
Not sure:	18.00%	9
Answered		50
Skipped		0



Nearly half (46%) felt it would have a positive impact if care and support were delivered in the community for a person with a learning disability and/or autism displaying challenging behaviours compared to just over one in four (28%) who believe this would have a negative impact. A further 18% were unsure and 8% preferred not to answer this question.

3. What impact do you feel it will have if care and support is being delivered in the community rather than in hospital for a service user's family members or carer?

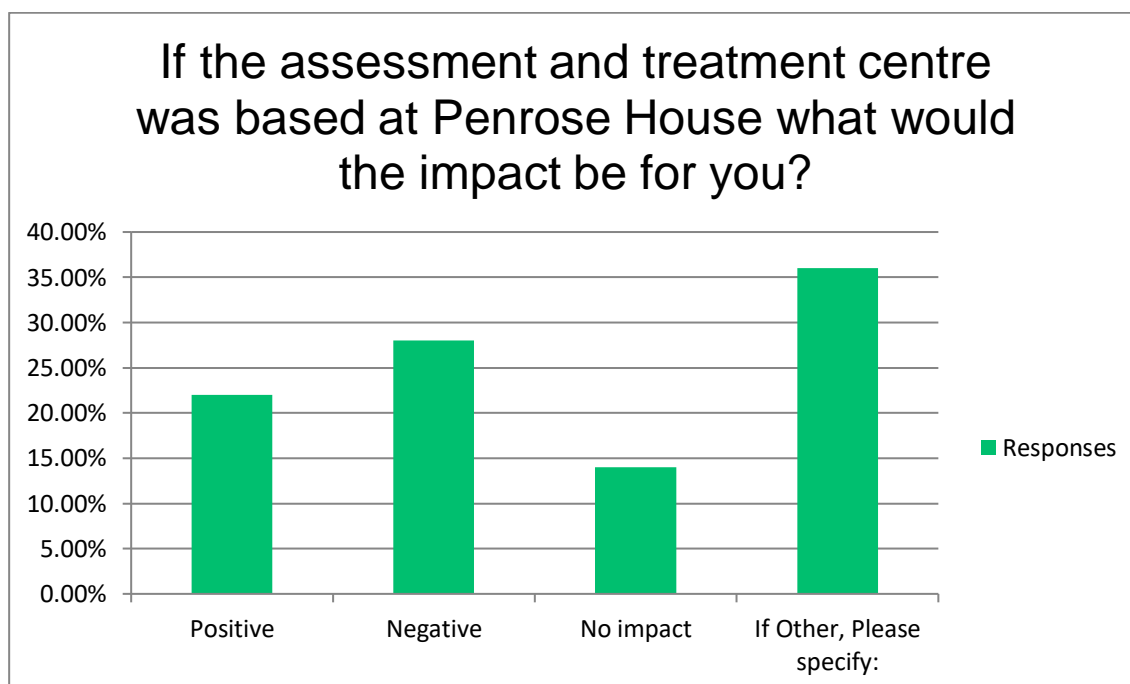
Answer Choices	Responses	
Positive Impact	44.00%	22
No Impact	0.00%	0
Negative Impact	14.00%	7
Prefer not to answer	18.00%	9
Not sure:	24.00%	12
Answered		50
Skipped		0



The greatest response (44%) came from those who felt it would have a positive impact on a user's family members or carers if care and support were delivered in the community compared to 14% who believe this would have a negative impact. A further 24% were unsure and 18% preferred not to answer this question.

4. If the assessment and treatment centre was based at Penrose House what would the impact be for you?

Answer Choices	Responses	
Positive	22.00%	11
Negative	28.00%	14
No impact	14.00%	7
If Other, Please specify:	36.00%	18
	Answered	50
	Skipped	0

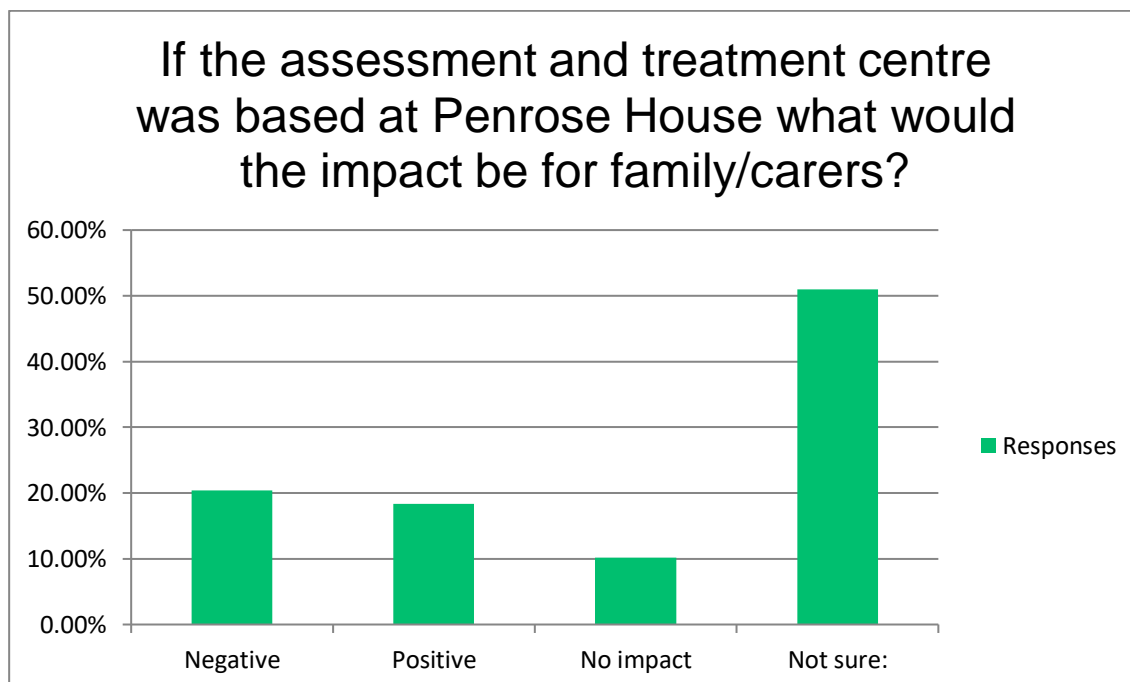


More than one in four respondents (28%) felt it would have a negative impact on them if the assessment and treatment centre was based at Penrose House, compared to 22% who believe this would have a positive impact. Of the 36% of 'other responses' recorded,

14 were unsure, three believed the distance to be an issue and one preferred not to answer this question.

5. If the assessment and treatment centre was based at Penrose House what would the impact be for family/carers?

Answer Choices	Responses	
Negative	20.41%	10
Positive	18.37%	9
No impact	10.20%	5
Not sure:	51.02%	25
	Answered	49
	Skipped	1



While 20.41% felt this would have a negative impact on families/carers, 18.37% believed this to have a positive impact. The largest number of respondents (51.02%) were not sure while 10.20% believed this would have no impact.

Questions 6 - 8:

Three questions were asked about the importance of specific support for people with learning disabilities in different circumstances. Of these, the majority of respondents felt they were all very important. Full results of these questions can be seen in the table below.

	Very important	Important	Not important	Not important at all	Skipped question
Support with daily life activities – help with day to day living e.g. washing, dressing, cooking, shopping	(24) 57.14%	(6) 14.29%	(10) 23.81%	(2) 4.76%	8
Communication – help communicating with people	(24) 54.55%	(7) 15.91%	(10) 22.73%	(3) 6.82%	6
Behaviour – help to understand which situations lead to challenging behaviour and how to avoid them or stop them getting worse	(21) 51.22%	(11) 26.83%	(9) 21.95%	(0) 0%	9

Questions 9 - 15:

The importance of help and support, and information and advice to reduce:

- The likelihood of challenging behaviour being displayed, and
- The frequency and severity of challenging behaviour.

Of these responses, the majority felt they were very important. Full results of these questions can be seen in the table below.

	Very important	Important	Not important	Not important at all	Skipped question
Personal support / being active in the community – help with making relationships and playing a part in family and community life	(19) 45.24%	(11) 26.19%	(10) 23.81%	(2) 4.76%	8
Environment / home life - help with getting a good quality of life e.g. participating in wider activities, the opportunity to follow interests, trying new things	(24) 57.14%	(5) 11.90%	(9) 21.43%	(4) 9.52%	8
Help to have the best physical environment eg housing	(18) 42.86%	(10) 23.81%	(9) 21.43%	(5) 11.90%	8
Help to deal with changing environments eg moving home, moving out of hospital, the right kind of housing	(25) 59.52%	(7) 16.67%	(9) 21.43%	(1) 2.38%	8
Family carer support/ additional support - giving breaks to those	(21) 48.84%	(7) 16.28%	(15) 34.88%	(0) 0%	7

being cared for, and their carers					
Information and advice – good information and advice to help make good decisions and to know what support is available	(22) 50%	(5) 11.36%	(14) 31.82%	(3) 6.82%	6

16. Please provide further details about your answers above and also tell us about any particular support that you feel would make a real difference:

Seven out of 50 respondents provided further details about particular areas of support they felt would make a difference, these comments include:

Responses
<i>All the above important but difficult to get the right trained people to carry out the above so many different words and swings in these peoples lives and obviously some more severe than others.</i>
<i>Money</i>
<i>Palliative and end of life care for people with learning disabilities needs to be considered, enabling people to live well until they die. Support with planning for end of life for people with LD and their carers. Please contact Gemma Allen at Mary Stevens Hospice for further information regarding our current work.</i>
<i>My GP surgery often registers patients who have come to study at Glasshouse College. Patients with Mod LD can be seen at Ridge Hill but those with primary ASD without LD end up with an inferior service as have to access mainstream mental health, often getting discharged when someone decides their ASD is the main issue and this is not commissioned. However often the needs of both ASD and LD patients are very similar, often the two conditions coexist. Can this unfair situation be addressed as part of these changes?</i>
<i>I believe all individuals need to have a quality of life regardless of their physical or emotional condition.</i>
<i>A single point of contact for families would be very useful</i>

Questions 17- 25:

When a crisis happens, how important are the following services to prevent hospital admission?

The importance of different services to prevent hospital admissions were commented on, of which the majority felt these were all very important. Full results of these questions can be seen in the table below.

	Very important	Important	Not important	Not important at all	Skipped question
Support with daily life activities – help with day to day living e.g. washing, dressing, cooking, shopping	(6) 75%	(2) 25%	(0) 0%	(0) 0%	42
Communication – help communicating with people	(7) 87.50%	(1) 12.50%	(0) 0%	(0) 0%	42
Behaviour – help to understand which situations lead to challenging behaviour and how to avoid them or stop them getting worse	(7) 87.50%	(1) 12.50%	(0) 0%	(0) 0%	42
Personal support / being active in the community – help with making relationships and playing a part in family and community life	(6) 85.71%	(1) 14.29%	(0) 0%	(0) 0%	43
Environment / home life - help with getting a good quality of life e.g. participating in wider activities, the	(6) 75%	(2) 25%	(0) 0%	(0) 0%	42

opportunity to follow interests, trying new things					
Help to have the best physical environment eg housing	(7) 87.50%	(1) 12.50%	(0) 0%	(0) 0%	42
	Very important	Important	Not important	Not important at all	Skipped question
Help to deal with changing environments eg moving home, moving out of hospital, the right kind of housing	(8) 100%	(0) 0%	(0) 0%	(0) 0%	42
Family carer support/ additional support - giving breaks to those being cared for, and their carers	(7) 87.50%	(1) 12.50%	(0) 0%	(0) 0%	42
Information and advice – good information and advice to help make good decisions and to know what support is available	(7) 87.50%	(1) 12.50%	(0) 0%	(0) 0%	42

26. Please provide further details about your answers above and also tell us about any particular support that you feel would make a real difference:

Three out of 50 respondents provided further details about particular areas of support that they felt would make a difference, these comments include:

Responses
<i>I think breaks for family and carers very important because of stress seems difficult to always get up to date advice.</i>
<i>Everyone has the right to develop.</i>
<i>Once again a single point of contact would be very useful so that families/carers do not have to keep repeating the information and they have an advocate to help them.</i>

Question 27 - 34:

When someone is discharged from hospital, how important are the following services to prevent them going back in?

The importance of different services in preventing someone from going back into hospital were commented on. Of those responding, all felt these were very important and important. Full results of these questions can be seen in the table below.

	Very important	Important	Not important	Not important at all	Skipped question
Support with daily life activities – help with day to day living e.g. washing, dressing, cooking, shopping	(7) 100%	(0) 0%	(0) 0%	(0) 0%	43
Communication – help communicating with people	(7) 100%	(0) 0%	(0) 0%	(0) 0%	43
Behaviour – help to understand which situations lead to challenging behaviour and how to avoid them or stop them getting worse	(6) 100%	(0) 0%	(0) 0%	(0) 0%	44
Personal support / being active in the community – help with making relationships and playing a part in family and community life	(5) 83.33%	(1) 16.67%	(0) 0%	(0) 0%	44
Environment / home life - help with getting a good quality of life e.g. participating in wider activities, the	(5) 83.33%	(1) 16.67%	(0) 0%	(0) 0%	44

opportunity to follow interests, try new things					
Help to deal with changing environments eg moving home, moving out of hospital, the right kind of housing	(6) 100%	(0) 0%	(0) 0%	(0) 0%	44
	Very important	Important	Not important	Not important at all	Skipped question
Help to have the best physical environment eg housing	(6) 100%	(0) 0%	(0) 0%	(0) 0%	44
Family carer support/ additional support - giving breaks to those being cared for, and their carers	(6) 100%	(0) 0%	(0) 0%	(0) 0%	44
Information and advice – good information and advice to help make good decisions and to know what support is available	(6) 100%	(0) 0%	(0) 0%	(0) 0%	44

35. Please provide further details about your answers above and also tell us about any particular support that you feel would make a real difference for people when they are moving out of hospital and into the community:

Four out of 50 respondents provided further details about particular areas of support they felt would make a difference, these comments include:

Responses
<i>The above important but not enough specialist people about, certainly suitable accommodation in friendly should be available for carers or family get sufficient breaks.</i>
<i>Travel</i>
<i>Doctors No house</i>
<i>Everyone deserves to feel safe and secure and able to develop.</i>

36. In your experience what stops or delays a person getting the right support in the community? (For example, not enough funding for community services being available or in place).

Many respondents expressed areas that they felt stopped a patient getting the right support in the community. They include:

Lack of family support and sufficient affordable care homes

Lack of funding for services

Lack of communication between the different services and professionals

The need for accurate and up to date information about services to be made available

The need for more qualified staff

37. From your experience, please tell us what can go wrong with being supported/ supporting someone in the community? (For example, not having the support in place for the person early on).

Many respondents expressed areas that can go wrong if supported/supporting someone in the community, this includes:

Lack of information for patients being discharged from hospital

Lack of support when carers are sick

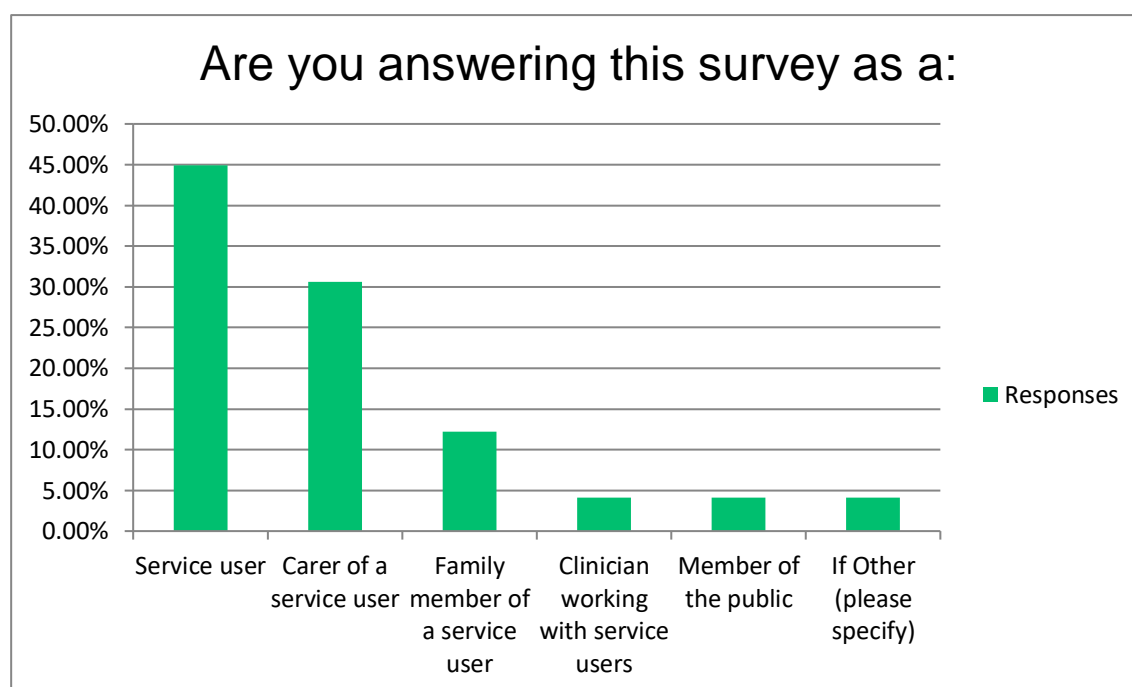
The right support might not be offered

Lack of communication and not planning for end of life care which can result in unnecessary hospital admissions

Not having appropriate funding in place to support patients

38. Are you answering this survey as a:

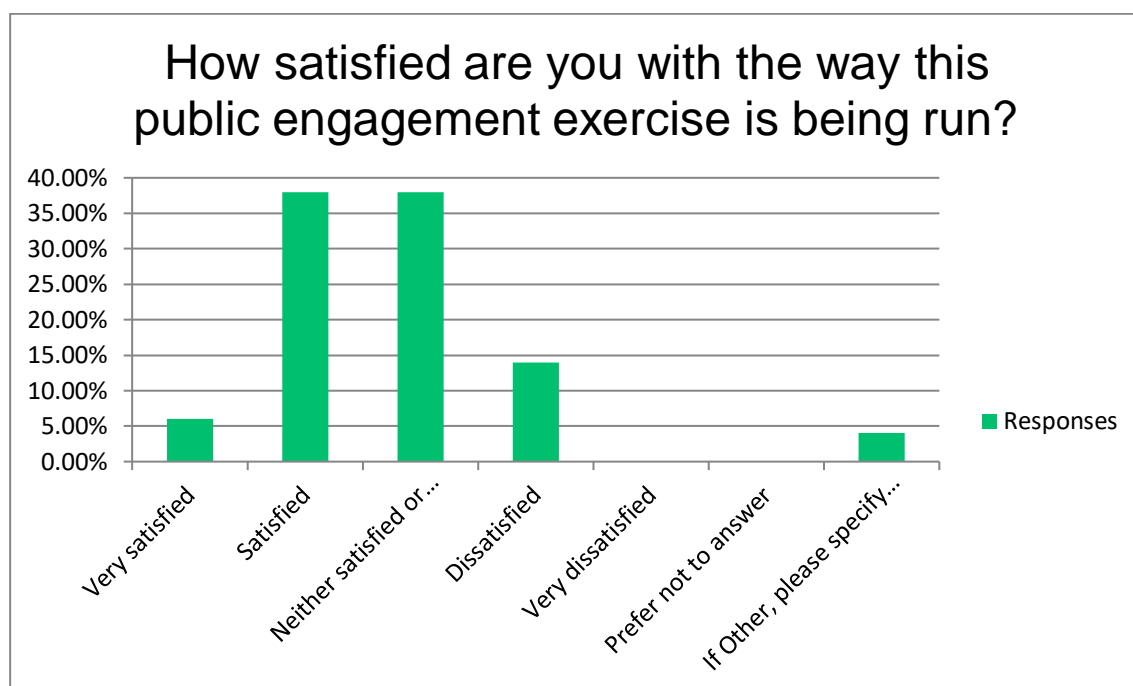
Answer Choices	Responses	
Service user	44.90%	22
Carer of a service user	30.61%	15
Family member of a service user	12.24%	6
Clinician working with service users	4.08%	2
Member of the public	4.08%	2
If Other (please specify)	4.08%	2
	Answered	49
	Skipped	1



The largest group of respondents completing the survey (44.90%) were service users followed by carers of a service user (30.61%).

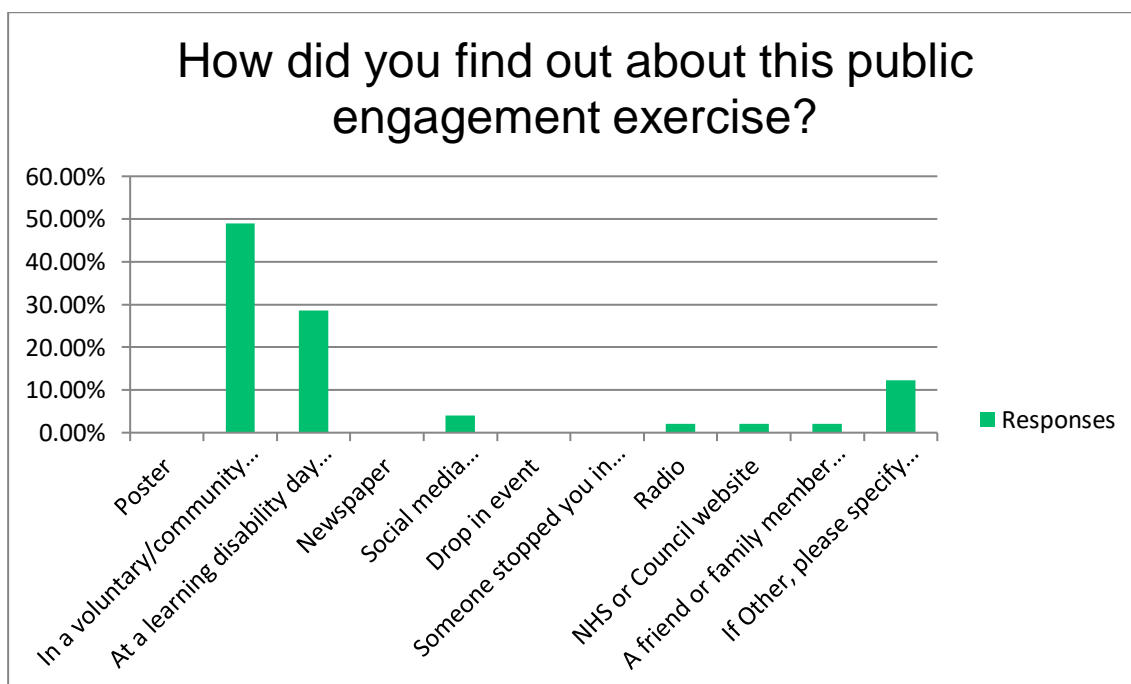
39 How satisfied are you with the way this public engagement exercise is being run?

Answer Choices	Responses	
Very satisfied	6.00%	3
Satisfied	38.00%	19
Neither satisfied or dissatisfied	38.00%	19
Dissatisfied	14.00%	7
Very dissatisfied	0.00%	0
Prefer not to answer	0.00%	0
If Other, please specify below:	4.00%	2
Answered		50
Skipped		0



40. How did you find out about this public engagement exercise?

Answer Choices	Responses	
Poster	0.00%	0
In a voluntary/community organisation	48.98%	24
At a learning disability day service	28.57%	14
Newspaper	0.00%	0
Social media (Facebook/Twitter)	4.08%	2
Drop in event	0.00%	0
Someone stopped you in the street (NHS Outreach Engagement Team)	0.00%	0
Radio	2.04%	1
NHS or Council website	2.04%	1
A friend or family member told me	2.04%	1
If Other, please specify below:	12.24%	6
	Answered	49
	Skipped	1



To view all equality data recorded see Appendix D.

7. Summary of Findings and Recommendations

7.1 Key themes

- **Positivity about the community focus offered by the new model.**

Most people were positive about the community focus of the new model. However, when asked about the location of the assessment and treatment centre, more people (28% of respondents) felt it would have a negative impact if the centre was based at the Penrose site; (22% believed this would have a positive impact). When carers and families were asked about Penrose as the preferred site, 20.41% felt this location would have negative impact; 18.37% believed the impact would be positive. The negative response to these questions will need to be mitigated if the final decision made is to have the treatment and assessment centre based at Penrose. It is recommended that the provider communicates the outcomes of this engagement process and continues to involve service users in the future developments of the community service model, for example in the design of any new buildings/facilities.
- **Relationship building**

The importance of relationship building and maintaining a good relationship between, patients, family members, carers and professionals.
- **Transport and access to the Penrose site for visitors**

Many people were concerned about travel to the Penrose site. It is recommended that the equality impact assessment is revisited, and travel and access for all reviewed.
- **Consideration for those with autism.**

It is recommended that a plan is developed to take into consideration the needs of adults with LD and autism
- **Consideration for those in transition (age 16 to 18yrs).**

It is recommended that a plan is developed to take into consideration the needs of those in transition.
- **The response to crisis**

It is recommended that consideration is given to the response to crisis.

- **The number of beds (10) in the new model**
Ongoing communication with patients and the public is recommended to mitigate concerns that ten beds will be enough for service delivery going forward.
- **Concerns about not having enough staff**
Ongoing communication with patients and the public is recommended to mitigate concerns about not having enough staff.
- To consider all feedback from the engagement process recorded in this report and appendices.

NHS Arden & GEM CSU

Engagement, Communications and Marketing

June 2019

