

Review of Cornwall Adult Partnership Boards

Nuala Kiely. Partnership Boards Officer. June 2018



“My daughter means the world to me. She can’t speak, but she laughs so much. I would do anything to help her get the care she needs even if I get tired, can’t sleep and never see my friends. Coming to the Board takes time and means I have to speak up to professionals who have never met someone like my daughter. If it means that she will receive high quality services and the care she needs, I would travel to the moon.”

Cate, carer

“I want them to listen to me when I come. It takes me a long time to come here. My friend is worried and she knows I am on a Board to speak to people. I said I would tell them the “service” isn’t working for her. I want to get the service right for my friend and other people who don’t come and are not ok about speaking “

Tom, self-advocate Learning Disability Partnership Board

“I am so pleased to be able to be part of the CAP. It’s not easy for me to meet new people but it’s important for me to take this opportunity and put forward my views. I believe we can change things for people with autism and I want it to happen”

Nick, self-advocate Autism Partnership



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Cornwall Partnership Boards

1. Executive Summary

Cornwall Council commissioned Healthwatch Cornwall (HC) to review the four adult Partnership Boards (PBs).

- Learning Disability (LD)
- Cornwall Autism Partnership (CAP)
- Older Persons (OP)
- Carers

They expressed a desire that PBs become more consistent in their approach, have better inter-Board communication and allow the voice of local agencies, stakeholders and lay people to be heard.

1. Aims

To review the PBs and find out if service users, self-advocates and carer members are:

- Listened to
- A part of the co-production of related strategies and services
- Reflective of their community

2. Methodology

The views and experiences of current and ex-PB members and other interested parties were sought through:

- face to face semi-structured interviews
- telephone interviews
- three focus groups
- attendance at four PB meetings and
- attendance at Cornwall Foundation Partnership Trust Carers Committee

This resulted in 81 contacts with council, NHS and voluntary sector staff, service users, self-advocates and carers from mid-March to May 2018.



An online survey was sent out to our email contact list for members of the Autism, Learning Disability and Older Persons Partnership Boards. There was limited distribution to the Carers Partnership Board members. Easy Read hard copies of an amended survey (appendix 1) were sent out via Mencap, Cornwall People First, Cornwall Health and Partners (CHAMPS) and Spectrum. Both surveys were publicised on the Healthwatch Cornwall website.

The survey resulted in 39 responses (appendix 1) which, in addition to the other quantitative data collected, enabled a good source of data to utilise.

3. Key Findings

3.1 Background

- The LDPB and Autism Partnership was set up in response to the Valuing People white paper (2001) and recommendations from the Autism Act (2009). Both had sub groups:
 1. Leadership Group (no longer meeting)
 2. Autism working group
- Carers PB began meeting shortly after and the Older Persons Board in 2016.
- There are other stand-alone health and social care committees, Boards and project groups within Cornwall working on issues in similar client groups including voluntary and statutory sectors. Joined up working may in turn strengthen the PB structure. (see: current PB structure appendix 2)
- Administrative support and PB development, as of 1 April 2018, is provided by Healthwatch Cornwall to all four PBs.

3.2 Membership

- There are large variations in the PBs contact list size, ranging from 94 in Cornwall Autism Partnership (CAP) to thirty seven for Carers.
- The numbers of service users, self-advocates and carers involved is well below an expected figure of 50%.
- There was only one older person in attendance at the last OPPB.
- There is a dependence on the voluntary sector to recruit and support self-advocates and carers.
- There are no demographics and equalities information available.
- It is unlikely that lay members reflect their community.
- Cornwall Council elected members who previously co-chaired, no longer attend.
- Reduction in attendance by Cornwall Council staff and NHS Kernow.



3.3 Terms of Reference (TOR)

- All four TORs are different and have not been reviewed recently.
- TORs are not being followed, including membership, meeting frequency, purpose and accountability.
- There are no current self-advocate or family carers as Chairs in LDPB and CAP.
- Meeting paper distribution is not reliably hitting deadlines.
- Websites have duplicate, incomplete information and different links. No one “go to” site for up to date information.
- PBs are regarded as having to report to Health and Wellbeing Board but this does not happen in practice.
- There is no cross PB working.

4. Meetings

- Are perceived to make a difference to services by 57% of respondents to the survey.
- It is evident that it is not known what powers PBs have.
- Service user, self-advocate and carer members do not have a clear understanding of what co-production is and this reflects in PB work.
- It is not obvious what questions and topics raised by service users, self-advocates and carers are within the remit of the PBs.
- PBs are seen as an under-utilised resource for consulting with “experts by experience”.
- There is some evidence of co-production with the CAP in Cornwall Council’s Autism Strategy.
- Within the PB meetings there is a space for self-advocates and carers to have a voice but this is often rushed.
- Without relevant decision makers present there are delays in questions being answered.
- Meetings are used as information sharing opportunities for professionals and service users, self-advocates and carers.

5. Partnership Boards around the country

- It appears that most Councils struggle with making PBs work.
- The number and types of PBs in local councils vary from 1-6.
- There is little research available to obtain “best practice”.
- Ineffective links with Health and Wellbeing Boards are common.



- Some have started to use a joint over-arching PB; others use a generic service user and carer led board.
- Forward plans and annual reports, drawn up by members, structuring the work of the PB keep PBs on track.
- Identifying one Council PB lead is crucial.
- Administrative support and PB development is increasingly carried out by local Healthwatch and voluntary sector organisations.
- Cross PB working and annual events strengthen the overall PB.
- Getting the right people in the right place at the right time is crucial.
- Senior council and elected officers involvement improves the effectiveness of PBs.

Recommendations:

General:

- A working group be set up of no more than 12 cross PB members including a Councillor and representatives from senior Council officers, NHS staff, voluntary sector, service users, self-advocates and carers to oversee changes identified by the review and Next Steps workshop.
- Continued commitment by Cornwall Council to support senior staff membership of the PBs.
- The integration of health and social care services be part of all PB working.
- Place co-production at the centre of Partnership Boards.
- Future consideration of setting up PBs or ways of working which include the voices of those with physical disabilities, sensory impairment and mental health needs.
- The Dementia Steering Group to become a PB in its’ own right or through cross Board working with the OP and Carers PB.
- A new Transitions Group/Board/Steering Group could work across the PBs.
- Consideration of locality boards.
- A financial commitment will be needed, from Cornwall Council, to ensure that the work of redeveloping the PBs continues in the longer term.

Terms of Reference:

- A generic TOR to be drawn up.
- The same reporting structure for each TOR.
- Each TOR to have an Easy Read and a fuller version.



- The LDPB Bill of Rights recognised in its own right, to be added as an appendix to the TOR and publicised more widely outside the PBs.
- Each TOR to be reviewed yearly and updated if changes in working take place during that time.
- Chair, Co-chair and Healthwatch Cornwall to ensure PB adheres to the TOR.

Membership:

- Election of service user, self-advocate and carer members to be transparent and follow same procedures across the PBs.
- A role description to be drawn up for Chair, Co-chair and other lay members.
- An agreed volunteer policy including expenses for all lay members.
- Targeted recruitment of working age adult carers, self-advocates with learning disabilities and those with autism as a matter of urgency.
- Open up membership of the Older Persons Board by self-defining an “older” person.
- Restrict membership to no more than fifteen people, half of whom must be self-advocates, service users and carers.
- Designated members will attend on an “as and when” when skills and expertise are needed.
- Collect demographics and equalities information for all lay members of PBs.
- More representation on the LDPB from family carers who can give a voice to their adult children with severe and complex needs.
- The most appropriate staff member to be attending each PB needs to be identified.
- Include the Chair of the Children’s Autism Partnership Board.

Meetings:

- Decision making to be enhanced by smaller, PB membership of “right people, right place, right time”.
- Focus on co-production of Cornwall Council strategies, policies and health and social care services.
- Thematic issues be discussed rather than individual ones.
- A two year work plan to be drawn up by each PB.
- Acknowledgement of the need to work with other PBs on issues affecting more than one group.



- Each PB to be co-chaired by a self-advocate, service user or carer with an elected officer.
- Training be provided for all PB lay members and additionally for co-chairs.
- Identify support needs of service users, self-advocates and carers which will enable them to fulfil their role as a PB member.
- A decision to be made about who is best skilled to provide support to self-advocates before, during and after meetings.
- Dates for meetings planned one year ahead.

Accountability:

- Consider the introduction of an over-arching Joint Partnership Board with senior staff from Cornwall Council, elected officers, NHS and service users, self-advocates and carers. (See: proposed PB structure appendix 3.)
- Before a significant change in Adult Social Care services, ideas should be brought to the PBs and co-production seen as the first step.
- All PB minutes go to Joint PB where Chair of that PB gives updates.
- Look at setting up working groups outside the PBs, including invited members with related experience and knowledge.
- Each PB to produce an annual report, presented at a yearly meeting of all PBs and also sent between:
 - a) Joint Partnership Board
 - b) Health and Wellbeing Board
 - c) Overview and Scrutiny meetings (as appropriate)
- Possibly a forum or group where questions related to more personal issues outside the PB scope can be addressed. A place for self-advocates, service users and carers to talk with council officers and other staff who may provide answers or direct them to where they may get them.

Others:

- Healthwatch Cornwall to continue to work with Cornwall Council to map voluntary sector organisations related to health and social care.
- A single access webpage with information on all the four boards, including minutes and meeting documents. Integrate links with events and other items of interest including consultations.
- Recognition that the PB development will require an on-going commitment from PB members together with an understanding that this will take time.



1. Background

Healthwatch Cornwall has been commissioned by Cornwall Council to review four adult Partnership Boards in the county and make recommendations for improvement to their future working. The individual Boards are both age and condition specific:

- Older Persons
- Carers
- Autism
- Learning Disability

Cornwall Council expressed a desire that PBs become more consistent in their approach, have better inter-Board communication and allow the voice of local agencies, stakeholders and lay people to be heard. This review was welcomed by PB members concerned about the increasing ineffectiveness of the Boards.

We looked at PB membership, terms of reference, accountability and ways of working. The views and experiences of current and ex-Board members and other interested parties were sought. It was carried out from mid-March to May 2018. To note, there is also a Care Home and Home Care Provider PB which is attended by provider organisations only and outside the remit of this report.

2. Aims

- To find out if the voice of service users, self-advocates and carers are listened to and effect changes.
- Identifying the role that PBs play in decision making and service planning within Cornwall Councils structure.
- To look at how PBs can have a wider remit in the current climate of integrated health and social care services.
- To determine whether PB membership is inclusive and reflects the community it represents.
- To look at how co-production fits in to the PBs work.



3. Review Findings

3:1 History of the Boards

The four Boards arose in different ways and their membership, ways of working successes and challenges reflect this.



Like elsewhere, the Learning Disability Partnership Board was set up in response to the Valuing People white paper published by the Department of Health in 2001. It was to be a mechanism of delivering the papers’ goals and remains a statutory requirement for each council, hence its’ protected position. A sub-group of the Cornwall Council Learning Disability PB called the Leadership Group was perceived as useful and effective. A reduction in senior staff attendance was one reason quoted as to why it stopped meeting, sometime around 2016. There are other groups outside of the LDPB which involve LD service users and carers in

developing services. These include the on-going LeDer and Transforming Care Projects. There is no inter-working with the PB although some people are members of both.

The Cornwall Autism Partnership (CAP) does not call itself a Board but functions in the same way. It arose following the Autism Act in 2009 and government recommendations in 2010. Since then the National Autistic Society in 2015 has issued its’ further support for the Boards. There is again a sub-group of the main CAP called the “working group” which meets regularly. It also has its’ own logo and an in-active website. Outside of the CAP, there are new groups emerging, looking at current topics such as the free health checks for people with autism. They are not directly linked to the CAP despite overlap membership.



The Older Persons PB had a later start in 2016 and despite originally having an inclusive membership, representation has changed over the past year.

The Carers PB would appear to have considerable member overlap with regional carer’s forums and the Cornwall Foundation Partnership Trust carers committee. The Care Act, 2014 does not make it a requirement for councils to have a Carers PB but in carer’s strategies, it is seen as a way to include carers in decision making around services for carers.



Healthwatch Cornwall provides administrative support for all the PBs as of 1 April 2018. This follows on from support by Cornwall Council and in the case of the Carers PB, Cornwall Rural Community Charity. Cornwall Council provided source funding for a LDPB self-advocate Chair from 2013-2015 and currently commissions a LD self-advocacy project to support self-advocates who attend the LDPB. Travel expenses are paid variously by Cornwall Council and Healthwatch Cornwall.

There are no specific Partnership Boards in Cornwall related to mental health, physical disabilities, sensory impairment or transitioning. A Dementia Steering Group, led by Dementia Alliance, has been meeting monthly since May 2016. It has been working on the dementia friendly community's project with Council funded administration support. This funding has recently ended.

3:2 Membership and meeting attendance

“The partnership board only works well if everyone needed is present to make decisions, share information and answer questions. There needs to be a commitment and accountability for attendance” Council staff member

To look at the membership and attendance at the four PBs, contact lists and meeting minutes over the past two years were studied.

Partnership Board	Contact List numbers	Average attendance of last 4 meetings up till April 2018	Service Users, Carers, Self-Advocates as a % of Contact List
Autism	94	25	21%
Carers	37	16	30%
Learning Disability	62	28	9%
Older Persons	50	15	20%

The contact lists didn't translate in to numbers of those who regularly attended meetings. There were also service users, carers, self-advocates and staff who attend more than one PB. This was most commonly within the LD and Autism PB. It is highly likely that some service users are missed off contact lists when they did not have an email address. This is definitely the case in the Learning Disability PB in which some self-advocates were addressed and minuted by their first names only, making it difficult to trace them.



3.3 The voice of service users, self-advocates and carers

“Many of the conversations are taken forward and things do change. It may be small but they all add up to delivering a better service” a carer

Service user, self-advocate and carer membership of all Boards made up far less than the 50% that would be considered good practice in PB working (Valuing People Now). This is a great cause for concern.

Although postcodes were not available for all PB members there was anecdotal evidence that those living in rural communities, were less likely to be involved in the PBs. This may be due to meeting venues and times, poor transport links and no remote access to meetings. There is no equalities information on service user, self-advocate and carer members so no comments can be made on age, paid work status, ethnicity and sexuality. Despite this, it would appear that men and adults in paid work are under-represented.

The majority of self-advocates on the LDPB were dependent on their individual supporter or associated organisation to travel and support them at meetings. It must be recognised that the dependence on voluntary sector organisations who are increasingly struggling with time commitments and resources may not be tenable. Cornwall Council Health and Making Partners (CHAMPS) scheme pays self-advocates for being part of a health promotion team. Their role extends to taking part in the LDPB and appears to work very well.

There has been a marked decrease in the number attending the Older Persons PB. There was just one older adult at the April 2018 meeting. The situation is critical. The population rise of older adults means consideration needs to be given to the age we call “older”. This would widen membership as it would include those not using services. Changes within some of the voluntary organisations historically involved with the Older Persons PB, has also meant that depending on this “method of recruiting” members needs to be addressed and other avenues looked at.

These issues were summed up by a lay member of the OPPB who has since left.

“When, I first attended I was a new resident and hoped to learn about services for older people in Cornwall. I have subsequently found that the Boards are for those currently involved with older persons’ issues and not for an individual who doesn’t, at present, use those services.”



Whether those who attend all PBs reflect those in their community, is debatable, in Cornwall as elsewhere. The diversity of adults with a LD, with autism, who are older or who are carers may never be fully represented.

Within both the LD and Autism PB those who have severe and complex needs are not well represented by family carers. There is no demarcation within the PB to allow this group to be supported to have a voice.

The Carers PB at present is predominantly made up of representatives from area forums which themselves are self-selective. Younger adult carers and those in paid work, in particular, are absent from the PB, yet are known to be a growing group. The link with the young carer's project has broken down. There are a significant number of ex-carers on the PB who are very passionate and knowledgeable but their experience of services is not always current.

3.4 Volunteering Role

What must not be forgotten is that the majority of service users, carers and self-advocates are attending the PBs as volunteers, giving their time and skills for free. There is at present, no allocated budget to allow payment for attendance at meetings or for acting as Chair or Co-chair. Travel expenses are paid by Healthwatch Cornwall and Cornwall Council but it is not a clear process. Creating a simpler consistent, timely method of paying expenses is needed. Printing meeting papers can be costly and needs to be recognised as such. A system which ensures paper copies are automatically sent by post is working. Non-monetary ways of supporting volunteers such as regular training, social events and refreshments at meetings may go towards retaining volunteers. The provision of paid respite to allow carers to attend has not been fully addressed.

“Why am I the one who gives up my own time, travels forty miles and gets no recognition? The staff get paid even when they haven't read their papers and don't speak. I know the Council don't have money but I'm helping them do their job” service user Older Persons PB

3.5 Staff attendance

Large numbers of Cornwall Council staff are involved with the PBs. There is an informally designated Council Partnership Board lead who has taken on the role, maintaining a positive continuous presence across all four PBs.

As concerns have arisen about the effectiveness of the PBs, less staff are attending. It is difficult to know whether poor attendance creates ineffective PB working or the other way round; probably both.



There are expectations by service users, carers, self-advocates and voluntary sector staff that Cornwall Council and NHS staff should answer questions about services and individual concerns, sometimes without being briefed beforehand or not working in the relevant department.

Staff comments:

“It feels like I have to take the blame. I wish I could help, I really do”.

“Same old, same old. Each meeting covers the same topics”

“We need to listen more to self-advocates but it's all such a rush with my phone buzzing”

“I enjoy coming to the PB cause (sic) I find out what's happening out there”

Comments from service users:

“It was great when he came and could tell me why my daughters benefit was going to stop”

“Different people come and the chain of thought is lost”

Overall service users, self-advocates, carers and members of the voluntary sector do question if the PBs are important to Cornwall Council or NHS staff. Are the PBs seen as a priority for staff with busy schedules? The Older Persons Board is “top heavy” with staff whilst the Carers PB has poor staff attendance. Why it may be like this isn't easily answered.

3.6 Elected Officers

Elected Councillors previously attended all four Boards and in the past chaired meetings. It is not obvious as to why they stopped coming. Workloads and Councillors leaving posts are possible reasons. Their involvement was seen positively and a useful direct link to a “real” decision maker and/or influencer. Service users, carers and voluntary sector members are concerned that their non-attendance suggests lack of interest in partnership working.



4. Terms of Reference

The terms of reference (TOR) should include the PBs purpose, structure and ways of working. All the PBs have a TOR (except the Cornwall Autism Partnership working group). They are markedly different from one another and, in looking at meeting minutes and attendance at the PBs, they are not adhered to. Two of the PBs TOR date back to 2014 with no evidence that they had been reviewed and revised since then. The Carers PB has a very lengthy detailed TOR with appendices whilst the Older Persons is two pages. Easy Read copies are available for both the LD and Autism PBs. In both, important details are lost which an alternative fuller TOR could include. Focus groups at all 4 PBs agreed that the TORs are not being followed nor are they workable for an effective restructured PB.

4.1 Meeting frequency

It is stated that Carers, Autism and Older Persons PB will meet quarterly and the Learning Disability PB six times a year. In practice the LDPB meeting frequency has not been as frequent. At times, meetings are cancelled at short notice for a variety of reasons including “key” members being unable to attend and venue cancellation.

4.2 Membership

Each TOR gives a lengthy list of members but, Carers PB excepted, there is no detailed way of electing them. The number of members (or suggested maximum) vary between twenty five and forty four. Looking back at original contact lists, the number of people invited far outnumbers those on the TOR. This is resulting in large PBs with people “coming along” rather than being elected members with an active well understood role. It is positive that there are so many people attending the PBs but this in itself is causing challenges. Decision making is difficult, as is giving time for all present to have their say. Large boards work more effectively when split in to smaller working groups with good planning and feedback.

There are Council, NHS and voluntary sector staff on the contact lists who could become invited guests (or remain on the mailing list) when their input relates to the topic rather than turning up as and when. Service users, self-advocates and carers are more consistent in their attendance but again there is not always evidence of how they came to be there in the start or when or how re-election takes place.



4.3 Chairing

“Leadership links ideas to power” voluntary sector staff member

At present, the Older Persons and Carers PB are chaired by an older person and carer respectively. The other PBs are currently without a Chair and have been intermittently facilitated by a Cornwall Council commissioner and Healthwatch Cornwall. To have a Council officer providing information, feedback and acting as a Chair conflicts and is unsatisfactory all around. Both the LD and Autism PBs’ TOR state that an Elected Councillor should co-chair the PB with a self-advocate. This no longer happens. The Carers chair has an out dated list of responsibilities within the TOR including attendance at:

- the service contract meetings on behalf of the carers PB
- the Carers Commissioning Group meetings

Recruitment of self-advocates and carers to take up the role of Chair and Co-chair for the LD and Autism PB is urgent. Before this can happen a role description and commitment to support the self-advocate needs to be put in place. Whether a financial remuneration is put in place for Chairs and Co-chairs across all the PBs needs to be decided.

“PBs cannot fulfil their role of co-producing and co-designing services without staff, service users and carers working together.” Voluntary sector staff member

4.4 Administration

The LDPB and Autism PBs received administrative support from Cornwall Council up until Spring 2016 when Healthwatch Cornwall (HC) took over the role, developing the Older Persons PB shortly after. There has been a recent changeover of support for the Carers PB from Cornwall Rural Community Charity (CRCC) to HC in April 2018.

Within the TORs, there are details about meeting papers distribution time with at the latest seven days before meetings for the Carers PB and up to one month before the LD and Autism PB. These targets are not always met. Easy Read copies of both the LD and Autism PBs agendas and minutes are available at each meeting but not all papers are provided in full non Easy Read. There have been requests from staff members who would like to review details in some documents.

Recording meetings was used in the past and may be useful for some members.

Lack of self-advocate chairs and vice chairs in the LD and Autism PB has meant that agenda setting has latterly been done by Cornwall Council (CC) officers and Healthwatch Cornwall. There is no evidence of agenda-setting meetings on the other PBs either. This has resulted in the PB members, at times, having no input to what will be discussed. There are standing items on the agenda allowing feedback from CC and NHS staff, voluntary sector, service users and carers from the area forums. As part of the LDPB



there is routinely a presentation by Cornwall People First self-advocates. Within very busy agendas it has been noted that time for self-advocates and carers to put across their points is limited and they can be side lined by staff feedback slots.

4.5 Websites

Cornwall Council has a Partnership Board (PB) web link. The Carers PB is linked to the Carers page whereas the others are on the Partnership Board area. Terms of Reference are all present but agendas and minutes are not all uploaded. Information about the PBs is also on Healthwatch Cornwall’s website but without meeting minutes; there has just been a link through to the council website.

Membership details and information updates are not included on either. The PBs are also publicised on the Support in Cornwall website and on other voluntary sector websites, for example the Parent Carer Council.

4.6 Venues

With travel times of 2 hours plus by car across the county and unreliable transport links, arranging venues for PB meetings has always been met with difficulty. There have been disagreements amongst PB members about different venues. From the TORs these various challenges have been noted but by no means solved. Choices include:

- Setting the venue most acceptable to most current members.
- Setting a “minority” venue to encourage new members living further away.
- Strictly rotate venues between East and West of the county.



Looking at the survey answers, the top locations were in areas where PB meetings are currently being held. The surveys’ limits mean it cannot identify if members of one PB liked one location more than another. Acceptability of meeting venues is also related to accessibility including free car parking being near and a good transport link. Travel issues can mean members are not able to arrive on time or have to hang around waiting for transport after. Room acoustics and room layout can also put attendees off. The idea of using tele-conferences and Skype as alternatives to travelling long distances may work. The survey showed 40% of respondents were interested in this option.



4.7 Accountability

The way in which the PBs report is unclear. Reporting to the Health and Wellbeing Board (HWB) is mentioned in the Older Persons TOR. It is also mentioned by other PB members that they report to the Health and Wellbeing Board but this is not within the TORs. Given that the meeting minutes are not sent to the Health and Wellbeing Board nor are they on its agenda, this is not so.

The HWB has limited formal powers as a non-executive Board. It builds constructive relationships between health, councils, voluntary sector organisations and the wider community but is not a direct decision maker with a budget. Healthwatch Cornwall have a place on it but this is not directly linked to their involvement with the PBs. There are questions which arise at PB level that can and can’t be answered at meetings. Currently questions as diverse as “I got charged for my bus pass application - why?” to “my wife has had four carers in four weeks - why?” are directed at council officers present at the PB or get lost in a series of emails between various council staff. This causes frustration and can lead to the same topics coming up at repeated meetings.

Annual reports are not produced and minutes are not shared between different PBs. PBs are acting individually but could work together on issues common to all.

“I didn’t even know there was an OPPB. We could have worked with them on the problems we are having on continuing healthcare” a Carer

“It will be useful to find out more about Universal Credit” The same comment from a self-advocate at the LDPB was made by a voluntary sector representative at the Autism Partnership.

“The lack of accountability is no doubt one reason why the Partnership Boards have been described as “talking shops where nothing happens”. Council staff member



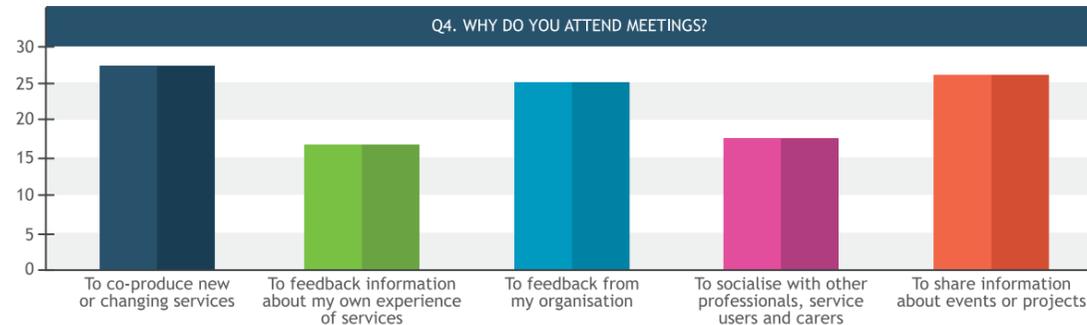
5. Meetings

5.1 Purpose

One of the PBs was described by a staff member as “a place which allows a frank exchange of views and can improve services. It is a place where experts by experience can co-produce services alongside staff.

It is not clear what actual powers the PBs have, what they can change or influence or even the next steps when a PB votes on an issue. Without this knowledge, it is not possible to establish what the actual remit for the PB is. This problem is common amongst many other PBs around the country.

In our survey, 57% of people felt the PBs did make a difference to services. The reasons why people attended vary and are complex.



The LDPB TOR has a list of Board tasks which is insightful and aspirational. It includes:

1. Make sure the views of self-advocates and carers help and advise services. (sic)
2. To improve the way they work and to agree how we co-produce services together.
3. Sign off the annual Health and Social Care Assessment.
4. Ensure that senior officers who can make decisions, on behalf of the agencies or organisations they represent, are at the meetings so that things can happen.

The ability to carry out some of these actions may have been weakened by the demise of the Leadership Board which followed the lack of attendance by decision makers and budget holders. The full LDPB has also suffered the same problem. Other items on the “To Do” list have been lost along the way and not always with any obvious reason.

There is no doubt that Partnership Boards have had important input in to various Council strategies including the Autism Strategy. Recently it has not been the case with the other PBs. As there are no current strategies being produced at the moment this may be a cause-effect problem. Meaningful co-production is not happening and other opportunities to engage self-advocates and carers in consultations is being lost. When the “right” person is at a meeting or has been



pre-briefed, answers and action points can be immediate but for some meetings it can take up to 2 months for a response. One Council staff member expressed concern that some self-advocates and voluntary organisations were waiting (up to three months) for the next PB to ask a question which may or may not get an answer.

The reasons PB members come to meetings may conflict:

- An opportunity to meet face to face with a Council officer (or NHS staff members less so) to get answers to questions which can be personal or have limited scope for the PB to act on.
- A place for staff to receive comments on strategies or commissioning plans a “five minute consultation” (a carers’ summing up).
- To find out what changes are happening to services and publicise what they are doing.

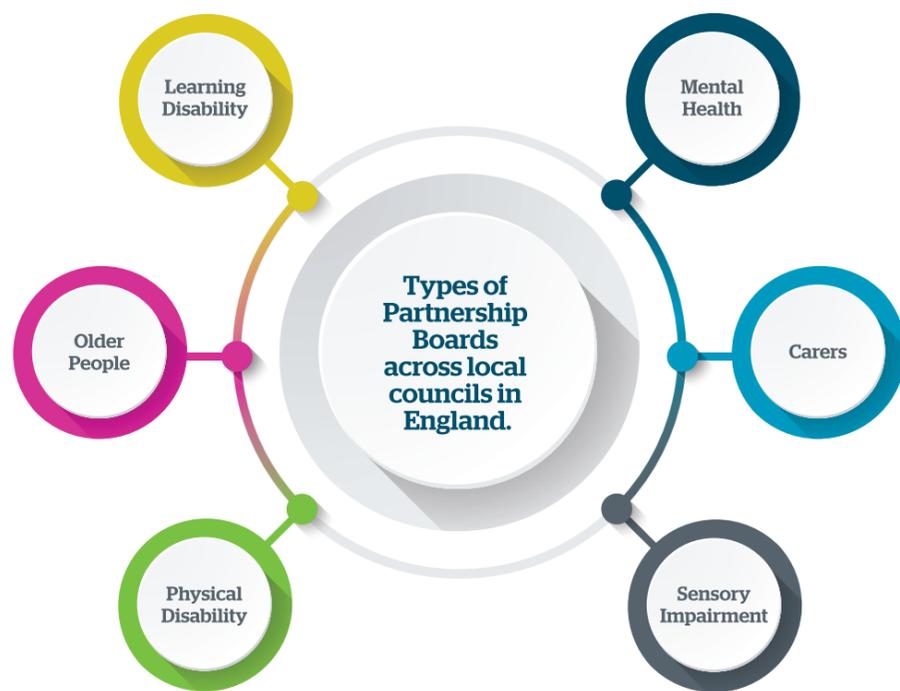
With these differences it can mean that not all groups go away satisfied.

What is and is not appropriate for discussion at the PBs is difficult to say alternatives which lie outside the PB may leave space in the meeting to concentrate on what service users and carers think about overall changes, plans, and commissioning intentions for services that will affect them or those they represent.

Some PBs have been fraught with personal differences amongst members and this has made some difficult to Chair. A non-elected and open door policy for self-advocates and carers on PBs may contribute. The idea of PBs acting as lobbying groups has been raised but it is clear that lobbying may divide its’ own members and specifically isolate paid staff whose job role prevents these actions.

6. Partnership Boards around the country

With an aim to locate “best practice”, we reviewed information on 12 local Council websites. By virtue of having available information online they were a biased sample. We found that the number and type of PBs vary a lot between areas. Whether the variation is connected to a commitment to partnership working (or lack of) by some councils or a stronger voice from some sections of the community is not possible to ascertain.



Some have LD and Autism PBs (Warwick and Cumbria) only. This would be in adherence to the statutory requirements following Valuing People and recommendations from the Think Autism paper. There are areas that combine LD and Autism PBs or do not have an Autism Partnership Board at all.

There are councils who still have only an LDPB whilst others have multiple PBs focussing on Older Persons, Mental Health, Physical Disability and Sensory Impairment. The criteria for membership of the older persons PBs is difficult to determine and relates to “an interest in” rather than an absolute age. One council named it “The living and ageing well partnership board”.

Northampton employs a specific partnership and involvement manager within a participation and development office. Council leads, where they exist, are usually connected to adult social care commissioning. Others depend on external organisations to support their PBs including local Healthwatch and voluntary sector organisations. Goodwill from the latter appears to back up paid council staff support.

In regards to accountability of the PBs, there is mention of reporting to the Health and Wellbeing Board (HWB) in most TORs but no evidence of feedback from the HWB on related actions. Overall most PBs remain autonomous. This seems to work where there is a strong membership including elected officers, senior commissioning staff, primary care and local NHS Trust representation along with voluntary sector, service users and carers. There are PBs with robust work plans and annual reports which are reviewed. A good example being Northampton LDPB with a three year forward plan, and London Borough of Enfield Councils’ LDPB Big Issue plan.

There is little research about PBs except Fyson and Fox (2014). They looked at the tensions in the involvement of people with learning disabilities in strategic planning. The paper highlights the struggles that LDPBs have to fulfil their dual role of operating inclusively and achieving inclusive outcomes. This could be said to be true of other PBs too. Guidelines for Good Learning Disability Boards in Department of Health 2009 publication appears to have been lost along the way.

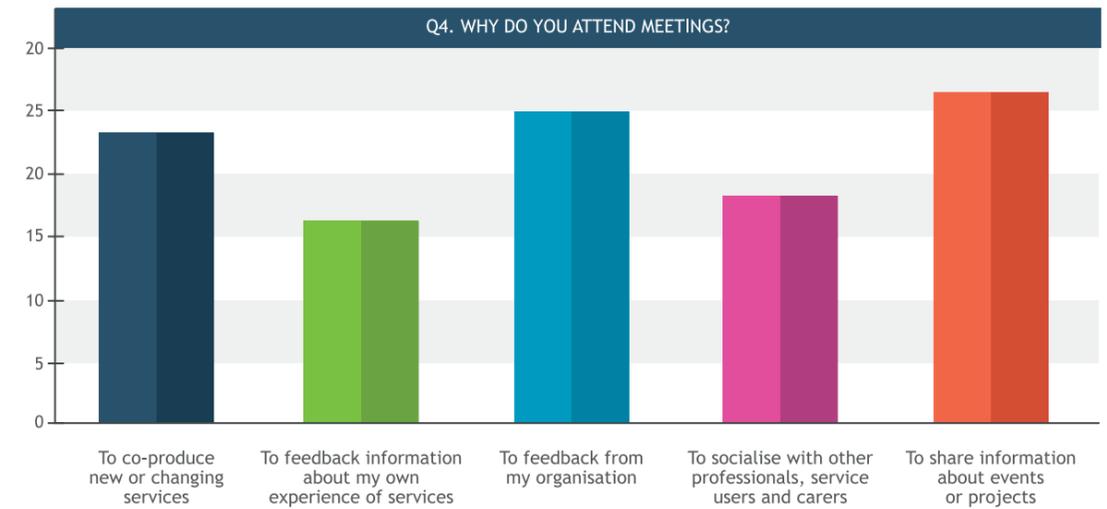
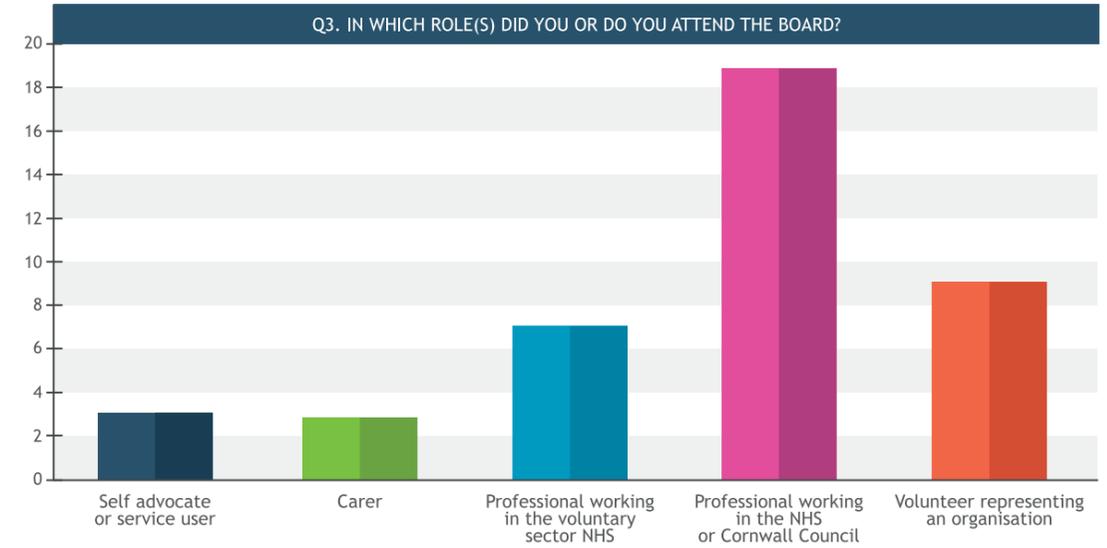
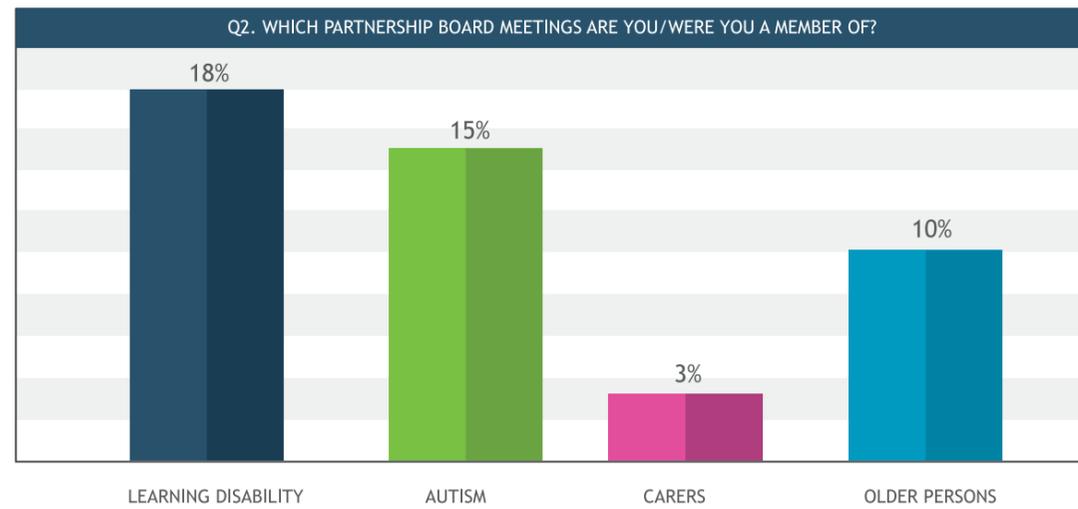
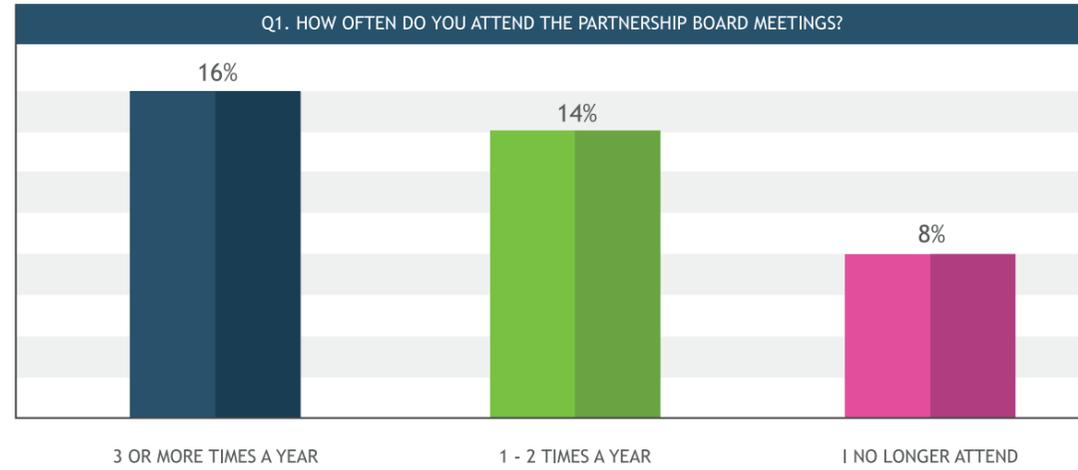
There has been one comprehensive review of Partnership Board arrangements. This covered London Borough of Haringey (Green R. 2016) and the LD, Autism and Adults (which included mental health, carers and physical disabilities) PBs. It highlighted difficulties with communication and trust between council staff and service users and carers. It also reports that a lack of accountability and actions following meeting discussions left staff, service users and carers frustrated and resulted in a drop off in attendance. Family carers described not feeling listened to and that adults with complex learning disabilities did not have a voice. There were two very large LD and Autism PBs and a small sized adults PB. The latter showed more effective decision-making and better relationships between PB members. A joint PB was introduced following the review and links made to another user and carer led Co-Design Group.

References:

- Healthwatch Cornwall proposal to review Cornwall Partnership Board arrangements.
- Department of Health (2001) Valuing People: A new strategy for learning disability for the 21st Century.
- Department of Health (2009) Valuing People Now: A new three year strategy for people with learning disabilities
- Department of Health (2009) Good Learning Disability Partnership Boards
- Department of Health (2009) Autism Act
- Think Autism - the Autism Strategy (2014)
- The Care Act (2014)
- Cornwall Council Autism Partnership, Terms of Reference, 2014
- Cornwall Council Learning Disability Partnership Board, Terms of Reference, 2014
- Cornwall Council Older Persons Partnership Board, Terms of Reference, 2016
- Cornwall Council Carers Partnership Board, Terms of Reference, 2014
- Fyson, Rachel and Fox, Liz (2014) Inclusion or outcomes? Tensions in the involvement of people with learning disabilities in strategic planning.
- Green, Roger (2016) Review of the London Borough of Haringey Adult Services Partnership Board Arrangements

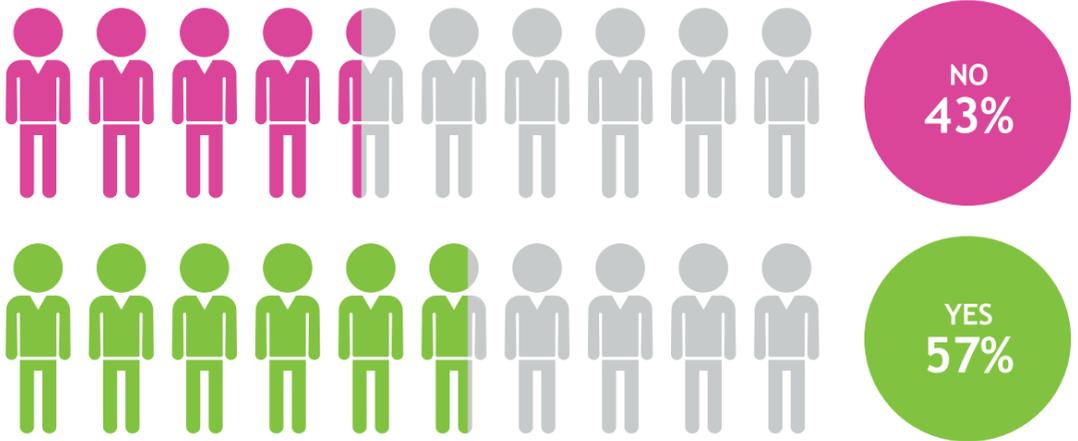


Appendix 1 Survey

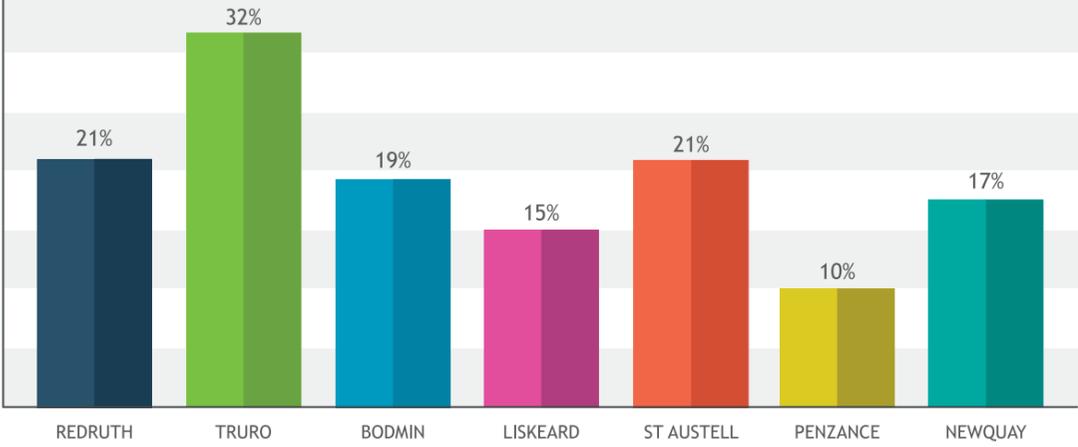




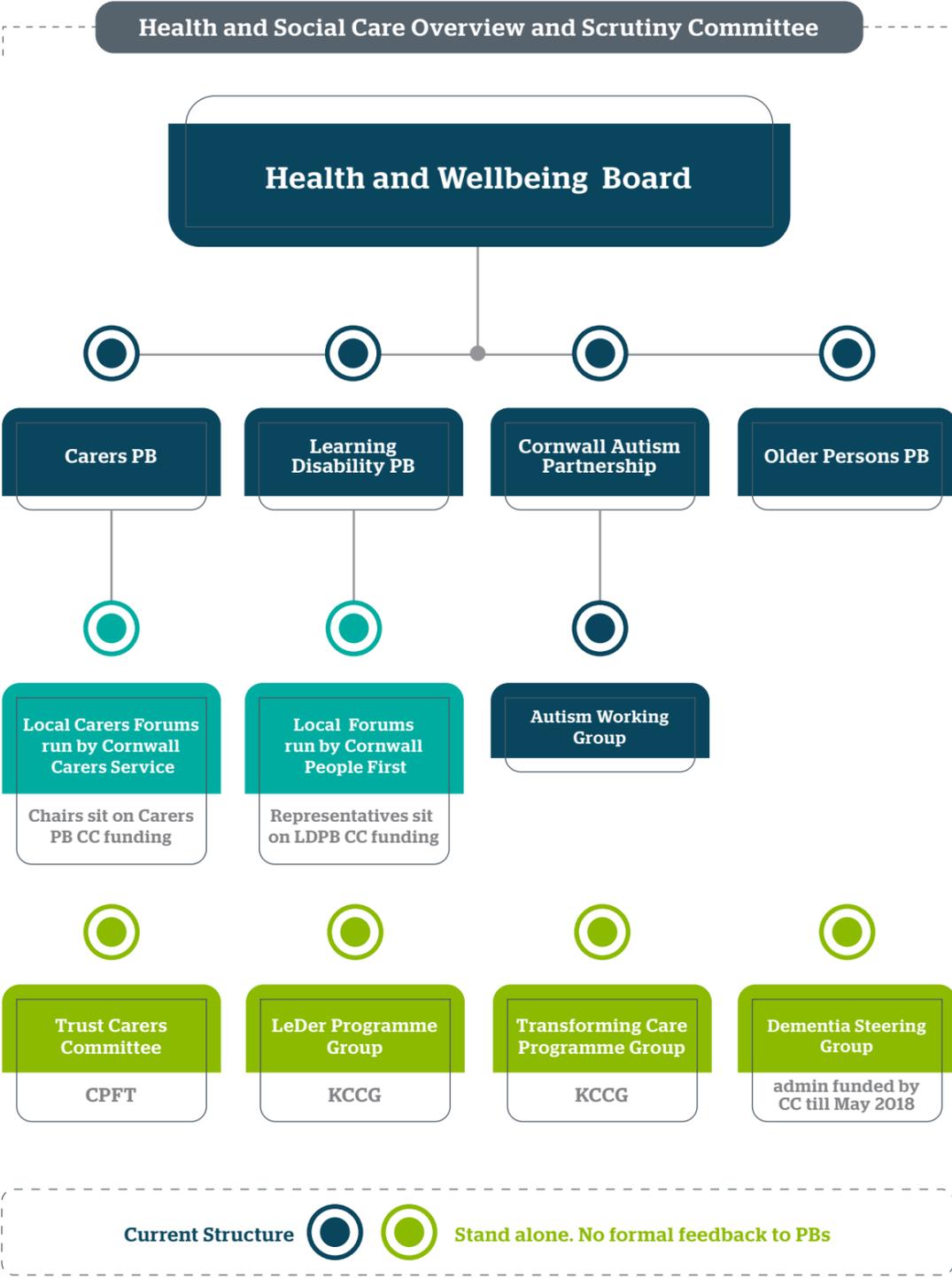
Q5. DO YOU THINK THAT PARTNERSHIP BOARDS MAKE A DIFFERENCE TO SERVICES?



Q6. WHICH LOCATIONS ARE MOST CONVENIENT FOR YOU TO ATTEND?



Appendix 2 Current structure of Partnership Boards





Appendix 3 Proposed structure of Partnership Boards

