Professional Liaison Group (PLG) - Review of the standards of conduct, performance and ethics, 16 December 2014

Service user and carer feedback

Executive summary and recommendations

Introduction

A number of activities have taken place as part of the review of the standards to benefit from the feedback of service users and their carers.

The attached paper looks at the common themes in these activities, identifying where they are addressed in the draft and noting any gaps.

Decision

The PLG is invited to discuss the attached paper.

Background information

None

Resource implications

None

Financial implications

None

Appendices

Connect (2013). Standards of conduct, performance and ethics – connect review

Date of paper

5 December 2014

Service user and carer feedback

1. Introduction

1.1 The HCPC undertook a range of different activities with service users and carers to gather feedback about the existing standards which has informed this review. This included the following activities.

- A joint workshop with patients with experience of cancer care and their carers hosted with Macmillan Cancer Support. A further workshop was run by the HCPC at the Macmillan Cancer Voices conference.

- Two workshops were held with service users with hearing impairments and their carers at meetings of the charity Hearing Link.

- A market research agency, ‘The Focus Group’, undertook interviews and focus groups with service users and carers with wide experience of contact with HCPC registered professionals. They also undertook focus groups and interviews with registrants.

- Connect, a charity which works with people with aphasia, undertook a piece of focus group research with service users and carers. They looked at expectations of health professionals and how accessible the standards were to this group of service users. This report is appended because the order of the draft standards has been modelled most closely on the authors’ recommendations (although this reflects well other feedback including the report from Shaping our lives).

- Shaping our lives, a service-user led organisation, carried out interviews and focus groups with service users in social care and their carers. The service users and carers involved had a wide range of experience of all HCPC registered professions. They also worked with another organisation who looked at how accessible the standards were to people with learning disabilities.[1]

1.2 Service users and carers fed back about their expectations of health and care professionals as well as feeding back about the accessibility or content of specific areas of the existing standards.

1.3 The outcomes of these activities have been fed into the ‘thematic papers’ considered by the PLG to date and have also influenced each draft of the standards.

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[1] Shaping our lives (2013). Standards of conduct, performance and ethics – service user and care consultation.
http://www.hcpc-uk.org/publications/research/index.asp?id=735
(N.B. The Connect and Shaping our lives reports were papers to note at the June 2014 meeting of the PLG.)

1.4 The Executive has looked across all the feedback and produced a table overleaf which lists the main themes in responses and the aspects that service users more frequently identified in feedback generally, or about specific standards, as being important to them and the care, treatment or other services they receive. The commentary column then identifies where this theme is covered in the draft and discusses whether there are any gaps that might be considered by the group.

1.5 Service users and carers engaged with the standards in different ways in each of the activities and often reflected on their own experience of the care, treatment and other services of their health and care professionals. The feedback from service users and carers provided a rich set of ‘data’ and reducing this to a series of themes like this might appear to ignore some feedback that we received. This is certainly not the intention – all the feedback has been reviewed and re-reviewed and in many cases has directly led to changes to the draft being considered at this meeting. This has included adding additional standards and amending some of the language used to make it clearer and more accessible. For example, service users with learning disabilities in the Shaping our lives research said that words like ‘limit’ and ‘inform’ in specific standards were unclear to them, so minor amendments were made to try and improve clarity wherever this was possible.

Theme	Aspects	Commentary
Partnership and respect Standard 1: Promote and safeguard the interests of service users and carers	• Treat people as individuals / treat the person, not the symptoms / treat the whole person (holistic). • Treat people with respect and dignity. • Consider people as partners and experts in their own care. • Respect peoples' rights to make their own choices and be involved in decisions about their own care / empowerment. • Ask if someone else should be involved in their care. • Be friendly / caring / compassionate / empathetic / patient / human / understanding / reassuring. • Non-discriminatory behaviour and attitude / cultural awareness. • Be punctual.	This theme is well reflected in standard one of the draft. The standards place more emphasis than before on treating service users carers as individuals and with respect; working in partnership; and empowering service users to make informed decisions. The new proposed standard 2.1 – 'You must be polite and considerate' – uses wording in another regulator's code and is intended to try and capture the frequent feedback about the personal qualities that service users and carers expect to be demonstrated by their professionals. The proposed draft (standards 1.5 and 1.6) means that expectations about working in a non-discriminatory way are clearer and stronger than before.
Communication Standard 2: Communicate appropriately and effectively	• Listen to people to find out their needs and wishes. • Give people explanations in a way that they can understand / use straightforward language. • Give information at every stage of care / treatment / services.	Standards 2.1 to 2.4 were added to reflect the feedback here from service users and carers in a simpler, clearer way than that in the last draft. Registrants need to listen to service users and carers; give them information

	• Communicate well with other professionals and work as a team / share information (when expected to or with permission). • Get consent / permission for care and treatment (having given the service user the information they need to decide). • Reflect use of electronic communication. • Standards should reflect and enable joint working. • Agree and use communication method preferred by the service wherever possible. • Be able to speak good English. • Take time to get to know you / understand your needs.	is an accessible way; and try to meet their language and communication needs where they can. Communication in English is a competency addressed in the HCPC's standards of proficiency for each profession.
Knowledge and skills Standard 3: Work within the limits of your knowledge and skills	• Have the training, knowledge and skills to do your job. • Know your boundaries and check if you don't know something. • Keep knowledge up to date / seek support.	
Report concerns / whisteblowing Standard 7: Report concerns about safety	• Report concerns / whisteblow about colleagues when necessary. • Protect vulnerable users. • Be honest generally (including about errors).	A common theme was reporting concerns or whisteblowing. This is well reflected in the draft.

Standard 8: Be open when things go wrong		
Behaviour, trust and honesty Standard 5: Respect confidentiality Standard 9: Be honest and trustworthy	• Not abuse your position of power. • Be honest. • Be reliable and do what you say you will. • Be organised and on time. • Have good personal hygiene.	This theme is largely well reflected in the draft. Some service users reflecting on their own experience talked about the importance of their professional being reliable – for example, turning up when they said they would, keeping them well informed and not breaking their promises. The code of conduct for social care workers refers to social care workers needing to be 'reliable and dependable' and 'honouring work commitments, agreements and arrangements and when it is not possible to do so, explaining to service users and carers'. Such requirements are not normally found in other codes and may not be suitable for inclusion. Some referred to the importance of good hygiene (generally or in connection with the previous infection control standard). This is now covered by standard six on risk.
Confidentiality	• Respect other's confidentiality and privacy.	This theme is well reflected in the draft. The wording ensures that communication

Standard 5: Respect confidentiality	• Reflect use of electronic communication and importance of confidentiality.	– face to face, in writing, electronic etc – is encompassed.
Record keeping Standard 2: Communicate appropriately and effectively Standard 10: Keep records	• Keep accurate records. • Allow service users access to records / respect rights to access records. • Share records with other health professionals • Read records before care / treatment / services (to support continuity of care).	Service users often only discussed record keeping when prompted to do so in the formal research activities – it often did not come up otherwise. The general expectation to keep records is included in the draft. Respecting access to records would be covered by the general expectation that registrants behave in a way which justifies public trust (and in accordance with legislation which addresses access to information). Sharing information is addressed in standard 2.5.
Accessibility (of the standards)	• Reduce number of standards and group them thematically. • Focus on personal qualities. • Use ‘person’ rather than ‘service user’ because its more collaborative. • Be more concrete and specific than abstract and general. • Use concepts and clear language which service users can understand. • Avoid jargon.	The number of standards have been reduced from 14 to 10 and a new order proposed based on the Connect research with service users and carers. This hopefully provides a more logical approach consistent with the feedback. Other feedback has already been noted to take forward in the next stage – e.g. a glossary already exists to the standards but it will be amended and added to.

	- Publish a text version and a more accessible version (e.g easy read). - Continuing service user involvement in developing, implementing and monitoring the standards. - Include a glossary. - Use bullet points.	

Connect –The Communication Disability Network
Consultancy on behalf of
The Health and Care Professions Council (HCPC)

Introduction

In July 2013 Connect began a 5 month consultancy project commissioned by the Health Care Professions Council (HCPC), to elicit the views of people with aphasia and their carers regarding the HCPC's Standards of conduct, performance and ethics.

Aphasia is a communication disability which results from damage to the communication centres of the brain usually caused by stroke or brain injury. People living with aphasia can experience a range of difficulties with communication from severe difficulties with understanding or producing any spoken or written language, to more mild difficulties perhaps with word finding or understanding complex language. These difficulties can have a profound impact on everyday functioning and can lead to reduced participation in life and isolation. Others with acquired neurological disabilities arising from, for example, Parkinsons Disease, Multiple Sclerosis, Motor Neurone Disease or indeed developmental disabilities may share these experiences and therefore the work described in this report has relevance beyond people living with aphasia.

Connect is a charity for people living with aphasia. It works to improve the lives of people living with aphasia and communication disability by equipping them to reconnect with life. Connect is a collaborative organisation, where people with aphasia lead and shape the work undertaken by the charity. People with aphasia advise on and participate in new projects and opportunities and collaborate in the development of training and publications. Many of Connect's members are extremely involved in raising awareness of aphasia in a variety of ways, and are experienced in consultation and focus group work.

This consultation sought to enable people living with aphasia and their carers to be meaningfully involved in evaluating the standards of conduct, performance and ethics set by HCPC and to provide feedback, based on their own experiences, which may inform changes to the standards.

Aims of the consultation

- To find out what service users with aphasia and their carers expect from their healthcare professionals.
- To find out whether the HCPC standards reflect these expectations.
- To explore whether the standards are accessible to service users with aphasia and their carers.
- To consider what changes might be necessary to the standards as a result.

Process of consultation

Recruitment of Consultation Group Participants

Opportunity to participate in the consultation groups was advertised at the Connect ‘drop in’ session, a weekly conversation and support session at the Connect London centre attended by up to 40 people with aphasia and a few carers. For those people with more severe aphasia, Connect staff were present to explain the project in an accessible way to enable them to understand and become involved if they wished. The people with aphasia attending ‘drop in’ present with a range of severity of aphasia, time post onset, age and ethnicity. The only exclusion criterion was people with cognitive difficulties that would have made processing the complex and abstract content of the consultations impossible.

Involvement in the project was on a voluntary basis and numbers at each focus group showed some variation, with 11 people with aphasia and 4 carers the maximum number at one session. Variable attendance was due to participant availability, (with the last session the least well attended due to having to change the day of the week). However, a core group of participants were clearly engaged and attended each session. In total 24 people with aphasia and relatives took part in the consultation. Participants ranged in time post onset of aphasia from 18 months to 13 years. Participants were of diverse ethnic origin and ranged in age from 23 to 78 years. There were an equal number of male and female participants. Due to the abstract nature of the material presented, most participants who elected to attend and continue with the focus groups had minimal comprehension difficulties; however they did present with a range of spoken and written expressive difficulties, including 4 participants with severe aphasia.

Individual Participants

In order to reach people with aphasia who are not able to or do not access Connect, 4 people with aphasia were interviewed in their own homes. These people were selected because they had received a Connect conversation partner (trained volunteer without aphasia) who had visited them in their homes for 6 months. We thus knew from volunteer feedback that they would be able to take part in the individual face to face interviews. They were 2 women and 2 men also of diverse ethnic background, but older: with ages ranging from 66 to 85. As a group, they had more severe physical disability but milder aphasia. One of this group had previously worked as a stroke unit Charge Nurse, and was particularly engaged with the content.

Facilitators

The Project was led and facilitated by 4 Connect staff: 3 Speech and Language Therapists with specialist aphasia experience, (including the Connect Chief Executive Officer) and 1 project leader with practical experience of aphasia consultation and focus group work. Trained volunteers without aphasia also supported the group consultation sessions.

Content and structure of the group consultations

Each group consultation session lasted for 2 hours and began with an accessible presentation to the whole group by one of the Connect staff, to introduce themes and plans for the session and to provide relevant background information; for example introducing the role of HCPC and the professions it regulates. Further activities, to explore themes in more depth and elicit individual experiences and expectations, were undertaken in smaller groups of 3-4 people with aphasia or carers. Each small group was facilitated by 2 people (either staff or volunteers), trained and experienced in supported conversation, to enable the people with aphasia to tell their stories and give their opinions openly. Resources to support communication exchange were prepared in advance, and included photos, drawings, key words and rating scales related to the HCPC themes.

Four consultation groups took place using progressive themes. The aims of these sessions are set out below:

Consultation Sessions	**Themes**	**Aims of Session**
1. July	What is the HCPC?	Introduce HCPC Introduce concept Of professional Standards
	Expectations of professional roles?	Generate expectations of professional people
2. September	Our expectations of healthcare professionals	Generate expectations

		of healthcare professionals
3. October	HCPC Standards	Look at and understand the HCPC standards of performance, conduct & ethics
	How do they compare to our expectations?	Compare them to our expectations
		Understand and agree changes we might recommend to content
4. November	HCPC Standards: How accessible are they?	Look at how accessible the HCPC standards are for people with aphasia
	Summary	Summarise our recommendations for possible changes to the Standards, both in Content and Accessibility.

Process and structure of the individual consultations

The individual interviews were deliberately carried out late in the process, (after the 3rd consultation group in October 2013) as it was thought that it would be helpful to be able to have the background of the previous consultations to inform the interview questions, and to make the process as concrete as possible for the interviewees. The individuals were shown the same materials as in the group sessions, and the same broad questions were asked of them. (A broad interview topic guide can found in **Appendix 6**). The interviewer (one of the Connect staff team who also one of the group consultation facilitators) carried out the interviews which were audio recorded and then transcribed. Each interview was between 45 minutes and 1 ¼ hours in length. It was more difficult to explain the consultation topics to the individual interviewees as they did not have the benefit of the group context and hearing the views of others. However, the themes they raised reflected the themes from the group consultation, most notably the focus on the *personal* attributes and care of the health care professional. Quotes from individual interviewees are included along with quotes from group members throughout.

Results / themes emerging from the consultation process

The first 2 consultation group sessions focused on developing an understanding of the participants' expectations of health care professionals.

Consultation Session 1

During the first consultation session the group were asked to think about professionals in general, and then drew on their own professional experience. Participants came from a diverse range of professional backgrounds including healthcare, engineering, law, transport and teaching.

As a result, they each brought different focus to the discussion, giving different weight to what they felt was most important. However all participants touched on certain key themes including professionals caring about their work and the people they work with, valuing others and treating people with respect and dignity, having appropriate knowledge and communicating effectively. Other expectations such as dressing appropriately, being organised and being on time were also discussed as important; however the group agreed that this was of differing importance depending on role (see **Appendix 1**).

Consultation Session 2

Discussions during the second session focused particularly on expectations of healthcare professionals, with participants drawing on their own experiences of receiving healthcare. The expectations generated from this session (**Appendix 2**) shared themes with the first session, however the tone differed subtly. Recalling their own experiences of receiving healthcare and their interactions with healthcare professionals produced a list of expectations which demonstrated a greater focus on 'patient' experience and required of professionals a greater emphasis on so-called 'soft skills' including:

Treating people with dignity and respect and caring about them.

"Their job is to care about you but they don't always. You're there, but you're not their main reason for existing, they have other things to do."

"Professionalism, empathy, um, consideration, respect."

"Treat patients the way you would have liked to have been treated"

"One, she lacked empathy… although she had confidence, she lacked…"

Being positive and reassuring and being mindful of people’s emotional state.

> *“She told me it would take at least 2 years for my speech to start to come back, my wife was in tears. 6 months later my speech had come back and I went back to tell her.”*

> *“good at modifying their communication. Taking time, face to face to listen”*

> *“be patient; make them (people with aphasia) feel that they know what they’re saying and that will build up their confidence”*

Examples of stories that appeared to generate particularly **negative emotions** often featured professionals who did not explain or collaborate sufficiently with the individual, or gave negative information in a blunt manner.

> *“And another physio didn’t turn up and I waited and waited and I went to reception desk and said I’m waiting for... and they said he’s not here today and I had an appointment. It was really hard to complain. So I didn’t bother... no explanation... so I gave up.”*

> *“I had a bad experience with a physio... basically they didn’t talk to me properly, they didn’t explain why we have to do this... and basically for me the exercise is very stupid, I didn’t understand why.*
>
> *“And they gave up on me... they sacked me!”*

Consultation Session 3

During the third consultation session the focus group performed a mapping process looking at the common elements between their expectations and the HCPC standards, and whether the HCPC standards reflected their expectations.

Through this process it became clear that there was significant overlap of themes generated by the focus group and the HCPC standards. However the group made specific comments about the thematic grouping of the standards, and suggested alternative wording/emphasis for many of the standards. **Appendix 3** contains the focus group's detailed comments on each HCPC standard, and the key recommendations of the group are summarised at the end of the report.

Following session 3, all material and comments generated by the focus groups (**Appendix 1, 2, 3**) were analysed by Connect staff for common and recurrent themes. 6 key themes emerged.

1. Partnership and mutual respect
2. Knowledge and skills
3. Communication, information and consent
4. Appearance and presentation
5. Honesty, confidentiality and trust
6. Reporting Concerns

Under each theme is a description using the key words and phrases generated by the focus group along with some quotations. (**Appendix 4**)

Consultation Session 4

In the final session the focus group gave feedback on the 6 key themes and descriptions, in terms of both content and accessibility. The group made some amendments to the wording and the ordering of the themes to group them together in a more logical order: firstly how they would like the healthcare professional to treat the individual, followed by themes about knowledge, then appearance and finally, reporting concerns should these standards not be followed.

The group discussed the theme of reporting concerns and whistle blowing in some detail. They felt it was important that an organisation fostered a supportive environment for its healthcare professionals and a protective environment for the public.

In addition to the above themes the focus group discussed 2 guidelines included in the HCPC standards which had not been included in the group's expectations:

- 'You should keep accurate records'
- 'You should deal fairly and safely with the risks of infection'

These themes had not been generated independently by the group, possibly as they feature less prominently in an individual's experience of healthcare professionals. However the group recognised their importance in good healthcare and therefore felt they should be included in their recommendations.

At the end of the final consultation session, the focus group felt that the 8 standards suggested below accurately reflected all their discussions and were expressed in the appropriate language.

Furthermore, the focus group felt it was important that healthcare professionals 'signed up' to these guidelines at the point of qualifying in their respective profession.

Revised standards suggested by the Focus Group

1. Partnership and mutual respect:

- You should treat the people you work with, with respect and dignity.
- You should always be aware of their emotional state and be positive and reassuring.
- You should treat the person not the symptoms, be friendly and value people.
- You should ask the person if there is anyone else they would like to be involved in their healthcare.

2. Providing information, communication and getting consent:

- You need to listen to people and find out their needs and wishes.
- You should give information and explanations in a way the person can understand.
- You should give information at every stage of care to the person and, where appropriate the family.
- Explain things in a straight forward way.
- You should not use jargon or acronyms.
- You should communicate well with other professionals and work as a team.
- After giving information you should ask the person for their agreement for treatment.

3. Honesty, confidentiality and trust:

- You should not abuse your position of power.

- You should be honest and respect people's confidentiality and privacy.
- You should be reliable and do what you say you will.
- You should be organised and on time.

4. Knowledge and skills:

- You should have the appropriate skills, knowledge and training to do your job.
- You should know your boundaries and check if you don't know something.
- You should make sure your knowledge is up to date or seek support.

5. Appearance and presentation:

- You should appropriately for your job and have good personal hygiene.
- You should not come to work under the influence of drugs or alcohol.

6. Reporting concerns:

- You should report any concerns about those you work with.

7. You should keep accurate records

8. You should deal safely with the risks of infection

General principles informing the recommendations

- The standards could be reduced in number, and grouped thematically.
- There needs to be particular emphasis on the personal qualities required by health care professionals.
- The standards need to prioritise accessible explanation and information provision.
- The suggested terminology (e.g. person rather than service user) reflects a more collaborative approach.
- The suggested standards are more concrete and specific rather than more abstract and general.
- The standards should be written in clear simple language without the use of jargon and acronyms. This would improve accessibility generally, not just for people with disabilities.

Communication Access

The group felt that as these standards are intended for a number of different groups of people e.g. healthcare professionals and different members of the public it may be useful to have several different versions available, including a straight text version and a more accessible version for people with communication difficulties. For this latter version they recommended:

- Short sentences

- One key idea per sentence
- Straight forward language, avoid abbreviations and jargon
- 14+ size font
- Bolding or underlining of key words
- Use of bullet points to break up long pieces of text
- Use of pictures to illustrate text

An example of one of the standards in this format can be seen in **Appendix 5.**

Summary and Conclusion

The participants who joined the consultation reported enjoying being involved in the process, as was demonstrated by the core group of people who attended every session. They felt it was interesting and important to have some input in shaping standards for healthcare professionals.

Appendix 1

Our Expectations of professionals in general

Dress appropriately for their job

Care about their work

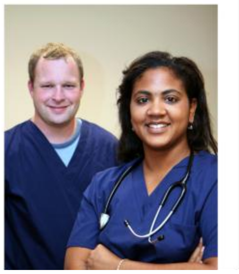
Care about the **people** they work with

Have the **appropriate skills** to do their job

Have the **appropriate knowledge** and **training** to do their job

Be **good communicators**

Treat others with **respect**



Be **Friendly**

Be **fair**

Value other **people**

Be **polite**

Not abuse **power**

Not break the **law**

Listen

Be **on time**

Be **confidential**

Be **honest**

Work **safely**

Be **organised**

Know their **boundaries** and check if they don’t know something

Appendix 2

Our expectations of healthcare professionals

Treat people with **dignity**

Treat people with **respect**

Treat the **person not** just the **symptoms**

Respect people's **privacy/confidentiality**

Be mindful of people's **emotional state**

Be **positive**

Be **reassuring**

Take time to **listen/find out** person's needs and wishes

Give **time** to each individual

Ensure knowledge is up to date or go and find out. Don't give inaccurate information.

Give **information and explanations** at every stage of care to the person and where appropriate the family

Explain things in a **straight forward way** (not jargon or acronyms)

Where possible have **continuity** of healthcare professional

Be **friendly**

Treat people as **individuals** (do not make assumptions based on age or stereotypes)

Be **punctual**

Be **reliable** and do what they say they will

Communicate with other professionals/work as a team

Be **flexible** and adapt to changing needs of the individual

Appendix 3

Notes from group exercise to map HCPC standards of performance, conduct and ethics to focus group expectations of healthcare professionals

HCPC standard	Focus group expectation/comments
1. You must act in the best interests of service users	The group felt this standard was very general They did not like the terms 'service user' and 'service provider' (too much like 'us' & 'them'), would like something that reflects more of a partnership which may then automatically imply some of our other expectations e.g. respect etc. They liked the words 'people' and 'partner'. It covered all of the group's expectations: - Treat people with **dignity** - Treat people with **Respect** - Treat **the person** not just the **symptoms** - Respect people's **privacy/confidentiality** - Be mindful of **people's** emotional state - Be **positive** - Be **reassuring** - Take time **to listen/find** out person's needs and wishes - Give **time** to each individual - Ensure **knowledge** is **up to date** or go and find out. Don't give inaccurate information. - Give information and explanations at every stage of care to the person and where appropriate the family - Explain things in a straight forward way (no jargon or acronyms) - Be friendly - Treat people as individuals (do not make assumptions based on age or stereotype) - Be punctual - Be reliable and do what they say they will - Communicate with other professionals and work as a team - Be flexible and adapt to the changing needs of the individual
2. You must	The group didn't like the use of the term 'service user'

respect the confidentiality of service users	Alternative suggestions: **Respect people's privacy and confidentiality**
3. You must maintain high standards of personal conduct	To include: - Personal hygiene/dress - Personal conduct – smoking, alcohol, not breaking the law - Meeting expectations of appearance, presentability and behaviour appropriate to your work
4. You must provide to us (and to any other relevant regulators) any important information about your conduct and competence	The group felt this could be represented as a more general standard about reporting misconduct and should reflect an obligation to report misconduct of others as well i.e. whistle blowing An alternative might be: **You must report misconduct, your own or others'.** This might include what would happen if you made a report.
5. You must keep your professional knowledge and skills up to date	The group were happy with this, but might want to include how this is measured?
6. You must act within the limits of your knowledge, skills and experience and, if necessary, refer the matter to another practitioner	The group were happy with this but may wish to alter wording to include **Give clear explanations, if you don't know say so and find out/refer on**
7. You must communicate properly and effectively with service users and other practitioners	The group wished to include: **Give information and explanations at every stage of care to the person and where appropriate their family** **Be friendly and take time with each person**
8. You must	The group had no comment

effectively supervise tasks that you have asked other people to carry out	
9. You must get informed consent to provide care or services (so far as possible)	The group felt this linked to standard 7, that communicating, giving information and explanations was an integral part of getting informed consent. Giving information in an accessible way and then obtaining consent.
10. You must keep accurate records	The group had no comment
11. You must deal fairly and safely with the risks of infection	The group had no comment
12. You must limit your work or stop practicing if your performance or judgment is affected by your health	The group were happy with this, but felt it overlapped with standard 4
13. You must behave with honesty and integrity and make sure that your behaviour does not damage the public's confidence in you or your profession	The group felt that this standard included many of their expectations from lists 1 & 2 and that there was overlap between this and standard 1: - Treat people with **dignity** - Treat people with **Respect** - Respect people's **privacy/confidentiality** - Take time **to listen/find** out person's needs and wishes - Ensure **knowledge** is **up to date** or go and find out. Don't give inaccurate information. - Give information and explanations at every stage of care to the person and where appropriate the family - Explain things in a straight forward way (no jargon or acronyms) - Be punctual - Be reliable and do what they say they will - Dress appropriately - Be fair - Do not abuse power - Do not break the law - Be honest - Work safely

14. You must make sure that any advertising you do is accurate	The group had no comment

Appendix 4: collated material from sessions 1, 2 & 3

1. Partnership and mutual respect:

- You should treat the people you work with, with respect and dignity.
- You should always be aware of their emotional state.
- You should be positive and reassuring.
- You should treat the person not the symptoms.
- You should be friendly and value other people.

> *"Physio was good . . . what made it good was a mutual confidence, they made me feel confident . . . positive"*

> *"The volunteers were the best . . . more interested in me, gave me more time and asked how I was"*

2. Knowledge and Skills

- You should have the appropriate skills, knowledge and training to do your job.
- You should know your boundaries in terms of knowledge.
- You should check if you don't know something.
- You should make sure your knowledge is up to date.

> *"The Royal college of Nursing says you've got to do um….so many hours every 3 years to be kept on the register"*

3. Communication, Information and consent

- You need to listen to people.
- You should find out their needs and wishes.
- You should give information and explanations in a way the person can understand.
- You should give information at every stage of care to the person and, where appropriate the family.
- You should explain things in a straight forward way, with no jargon or acronyms.
- You should communicate well with other professionals and work as part of a team.
- After giving information you should ask the person for their agreement for treatment.

“At the beginning of the week you get given your timetable and you didn’t have a full week at all . . .supposed to be having a full day of rehab, no one turned up on time . . . waiting . . .waiting . . .waiting . . .no communication, no explanations!”

“If all of them could just talk, communicate and say look I’m sorry about this . . . then that would be better”

4. Appearance and presentation

- You should dress appropriately for your job.

- You should keep good personal hygiene

> *“The physios came dressed for the job, organised, enthusiastic, brilliant!”*

> *“You can’t come with your hair down there, that’s a no no. Dress code reflects professionalism…and it gives people more confidence*”

5. Honesty, confidentiality and trust

- You should not abuse your position of power.
- You should be honest.
- You should respect people’s confidentiality and privacy.
- You should be reliable and do what you say you will.
- You should be on time or let the person know if you won’t be

> *“I had one SLT who was brilliant, she said she would come and she did!”*

6. Reporting concerns

- You should report concerns about others.
- It is important to maintain standards to protect patients.

connect
the communication disability network

Appendix 5. Example of communication accessible standard

Partnership and mutual respect:

You should **treat** the **people** you work with, with **respect** and **dignity**.

You should be aware of their **emotional state**

Be **positive** and **reassuring**

You should treat the **person** not the symptoms,

Be **friendly** and **value** other people.

Appendix 6: Topic Guide for individual interviews

Start with detailed explanation regarding the background to the project. Talk the interviewees through the consultation so far and show them all the accessible resources and power points used to elicit discussion.

1. Can I start by asking you to think about professionals in general (using the sheet of well known professionals). What characteristics might we expect of people doing this job?

2. Can I ask you to think about your own job? What job did you do? What did people expect from you in your role?

3. Now, with your personal experience of having been a patient. What qualities did you expect from the health care professionals looking after you? What was important?

4. Can you think of a health care professional you've met where you didn't have a good experience. Where it was negative? And if so, what made it negative? What was it about them?

5. Can you think of a health care professional where it's been a really good experience? Where they gave you really good care? Why was that? What made them so good?

6. (Showing the Standards of conduct, performance and ethics). What do you think about this as a person with aphasia? How accessible is this? How might you change it?

Appendix 7: Case Study; one of the Focus Group members

One of our focus group members, E, was interviewed in more detail. She is 46 years old, and 2 years post CVA (Cerebral Vascular Accident). We have recorded her direct speech in quotation marks.

‘I asked to get involved. I had just lost my mother and she had a lot of help from health care professionals. I wanted to talk about that. I had my own experience of the world. It seemed like a good opportunity to give back.

I attended all 4 sessions. On the whole it seemed a nice thing to do. Nice to be listened to. It was positive to feel like I had some role to play in talking about health care professionals. I realise a lot of it was not particularly relevant, but there were some things that really were. It was quite interesting. Other people in the group talking about very personal things…quite good. There was one clash between me and C (a relative) but so little, and we got there.

The woman (Anna) was very good at the start but at the time it was difficult to position it, and difficult to maintain momentum of where this was going. It would have been better if it was over 4 weeks not 4 months.

They discussed they’ll use it (*our focus group information*), but not how they will use it. Will they use pictures? It would be nice to see the finished product?’