



**Service User and Carer Consultation
Review of the Standards of conduct, performance and ethics
Of the Health and Care Professions Council**

Shaping Our Lives
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Executive summary

In 2013 Shaping Our Lives were commissioned by the Health and Care Professions Council (HCPC) to carry out a consultation with service users and carers to review the HCPC Standards of conduct, performance and ethics.

Shaping Our Lives conducted this qualitative research with 30 solo interviewees and a focus group, all of whom were service users (as defined by Shaping Our Lives) and many of whom were disabled people; some interviewees were carers. The research explored each standard in turn and also asked questions about awareness of the HCPC and the standards generally. We asked the Words and Pictures team at CHANGE to comment on the 14 standards in order to gather feedback from a group of adults with learning disabilities about the accessibility of the language used in the current standards.

Key findings

Interviewees were broadly in agreement with the current standards, and could see that most were relevant.

Most people agreed that the standards are applicable to all 16 types of registrant.

There is low awareness of the HCPC and the standards.

The three standards which deal with ethical behaviour (standards 1, 3 and elements of 13) have a high degree of overlap and need most revision.

Interviewees were keen to map their lived experience of using health and care services to reflect on how the standards were implemented in practice. There was some concern about the difference between the aspiration of the standards and actual delivery within the constraints of time, resources and budgets.

Interviewees had experienced a lack of disability awareness and some discrimination from service providers.

The standards are not accessible to all disabled people. Both the language used and the formats available need addressing.

Recommendations

Shaping Our Lives has made recommendations to inform the planned review of the standards in 2014-15 so that the new standards are fit for purpose from a service user perspective. Shaping Our Lives has also made recommendations about how the HCPC can communicate more successfully with service users. The recommendations are presented under five themes which reflect both the external environment and the issues of particular relevance to service users who are disabled people, and their carers.

- Being in control
- Integration and joint working
- Accessibility
- Considering equality
- Protection of interests

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Introduction

Shaping Our Lives has been commissioned by the Health and Care Professions Council (HCPC) to help with a review of the Standards of conduct, performance and ethics (the standards) prior to a public consultation process in 2014/2015. The HCPC is interested in examining how the standards are used, their accessibility to service users and carers and how ethical principles set by the regulator can best be translated into understanding and practice.

This report details the findings from 30 interviews and a focus group with service users (including disabled people) and carers conducted by Shaping Our Lives.

The HCPC is a regulator and its main aim is to protect the public. To do this, it keeps a register of professionals (registrants) who meet the standards for training, professional skills, behaviour and health ('health' here refers to the health of the professional). The standards were first published when the HCPC Register opened in July 2003 and were reviewed in 2008 with some more minor changes in 2012. The list of current standards is shown in Appendix One.

All professionals registered with HCPC will appear on their Register. They must keep to the standards which give levels of expected professional behaviour and provide protection for people using their services. The general public can report concerns about fitness to practise to the HCPC. There are 16 types of professionals on the Register including: chiropodists, hearing aid dispensers and social workers in England (a full list appears in Appendix Two).

The HCPC also publishes standards of proficiency, which are standards used to make sure the professionals they regulate have the knowledge and skills they need to work safely in their field of practice; these standards are not subject to review at this time.

Earlier in 2013 the HCPC commissioned The Focus Group to conduct research exploring registrants and service user views on the content and accessibility of the Standards of conduct, performance and ethics. Their findings have been reported separately but are referred to in this document when relevant.

In 2001 Shaping Our Lives published a Briefing Paper 'Putting The Person First' a result of their role in reviewing the codes of conduct of Social Workers). This is a quote used in that paper, which sums up how

service users feel about what matters to them. We feel that this is still as relevant in 2013.

‘They value courtesy and respect, being treated as equals, as individuals and as people who make their own decisions; they value [social care] workers who are experienced, well informed and reliable, able to explain things clearly and without condescension, and who ‘really listen’; and they value workers who are able to act effectively and make practical things happen... The way workers behave, and what they do or do not do, makes a big difference to how people feel about themselves and the quality of their lives’.

In this report *Shaping Our Lives* has occasionally discussed issues that are outside the remit of the research that was commissioned by HCPC. However, we have chosen to include the comments as they were raised by participants. We have highlighted where this occurs.

Definitions

Service users: The definition of 'service user' for the HCPC is someone who uses or is affected by the services of one of their registrants from the 16 professions regulated.

The definition of 'service user' for Shaping Our Lives' is different as detailed below. Service users may also be disabled people, but not necessarily. The term service user generally stretches to a wider group of people and includes homeless people, people with experience of long term care and people with drug and alcohol use issues. Shaping Our Lives sees 'service user' as an active and positive term, which means more than one thing. It is important that 'service user' should always be based on self-identification. But here are some of the things we think it means:

- It means that we are in an unequal and oppressive relationship with the State and society.
- It is about entitlement to receive welfare services. This includes the past when we might have received them and the present. Some people still need to receive services but are no longer entitled to for many different reasons.
- It may mean having to use services for a long time which separate us from other people and which makes people think we are inferior and that there is something wrong with us.
- Being a service user means that we can identify and recognise that we share a lot of experiences with a wide range of other people who use services. This might include, for example, young people with experience of being looked after in care, people with learning difficulties, mental health service users, older people, physically and/or sensory impaired people, people using palliative care services and people with drug and alcohol problems.

This last point about recognising our shared experiences of using services, whoever we are, makes us powerful and gives us a strong voice to improve the services we are given and to give us more control and say over what kind of services we want.

Service users welcome the use of the word 'support' alongside 'care', and sometimes in place of it. People we interviewed are very used to the term service user to refer to them, or people they care for. Some might not like the term but it is widely adopted and understood in this context.

We recognise that the HCPC use the term service user in a wider sense. In this report however we will use the term service user as defined by Shaping Our Lives.

Disabled People: In this report disabled people is used in its broadest sense to include people with physical and sensory impairments, those living with long term conditions and life-threatening illnesses, people with learning disabilities and those living with mental health issues.

Traditionally people have been viewed through a lens of what is wrong with them e.g. they are visually impaired, they are mentally ill, they have an alcohol problem. This is referred to as the medical model. The social model turns the tables and says people are disabled because of the prejudice they face. Using the social model helps identify solutions to the barriers disabled people experience. It encourages the removal of these barriers within society, or the reduction of their effects, rather than trying to fix an individual's impairment or health condition.

The social model is the preferred model for disabled people. It empowers disabled people and encourages society to be more inclusive. Although other people who use social care and support services are not explicitly covered by this model it is a useful reminder to look at all service users in the round, what is really causing the problem in their lives, and not just through a narrow definition of what is 'wrong with them'.

'Sometimes personal conduct needs to be less medicalised and more humanised. Meaning that when a disabled person comes into contact with any kind of practitioner there is a tendency to see disability first and not the person.'

Carers: A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Professionals: is a term employed in the context of this report to mean a person providing one of the 16 professions regulated by the HCPC. It is a term used interchangeably with service providers and practitioners. Professionals appearing on the HCPC Register are known as registrants.

The wider context

Obviously since the HCPC last reviewed the standards in 2008 there have been changes to the external environment within which health and care professionals operate, and we have reviewed ones here which are of relevance to service users, particularly disabled people and carers. We are asking how should standards which provide a framework for regulating the conduct, performance and ethics of individual practitioners take account of:

- Equalities and Health legislation, a growing understanding of active participation in health and care services by the end user, in the barriers to accessing new communication technologies,
- a greater public awareness of regulation failures,
- a greater awareness of the role of practitioners in regulation and whistle-blowing.

Choice and control

There has been a growing movement to involve service users as leaders in their own care. One of the interviewees in this review welcomed the HCPC's user involvement:

'We have moved to a more collaborative way of dealing with things, rather than them [the HCPC] and us.'

Started by the disabled people's movement in the early 1980s as a campaign for human rights, in more recent years user led service delivery has been adopted by the public sector in recognition that involving people in decisions about their care and support early on can make the key difference to more positive health and quality of life outcomes (Health and Social Care Act, 2012). The Care Quality Commission reports that problems often arise in people's quality of care where there had been a lack of person-centred planning, with little information about people's individual preferences (CQC, 2012). To provide a framework for involvement, the Health and Social Care Act incorporates Public Involvement Duties for Clinical Commissioning Groups and local authorities (via Healthwatch). Do the current standards reflect the 'no decision about us, without us' ethos.

The HCPC and other consumer champions

Patients and other service users are aware of PALs as a well-established means of making a complaint about services received in a health context. Healthwatch is becoming established now and it is planned to grow as a consumer champion. Although beyond the remit of this research, a question for the HCPC is how its profile impacts on service users, how it encourages complaints about the practitioners on its register and how it relates to PALs and Healthwatch.

Integration and joint working

The Department of Health states that improving quality of care is at the heart of the Health and Social Care Act 2012 and that one key means to achieve this is to ensure care is integrated around the needs of patients. The Act seeks to encourage and enable more integration between services.

The benefits to service users are tangible. As Sass and Beresford report states “there is a whole life to be lived and managed – with often far greater consequences than any single clinical encounter or social care appointment can ever address positively.” (User-driven commissioning, Disability Rights UK Shaping Our Lives, 2012). Joint working between agencies is a vital component of enabling service users to keep the whole engine running.

Going forward the HCPC needs to consider how their standards enable joint health and social care working and maintain the best interests of service users.

Provision of good and services within an equalities framework

The Equalities Act 2010 replaced previous legislation such as the Disability Discrimination Act and the Race Relations Act. The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society, such as the provision of goods and services, as those provided by health and social care practitioners. How robust are the current standards in relation to equality of provision and prevention of discrimination?

Online communications: the barriers for disabled people

Another change which needs to be considered is the technological advancements of this century and the benefits and disadvantages they bring to communication between practitioners and service users, and between practitioners.

Because of the rapid growth of new technologies as communication tools, barriers to new technology also have to be recognised by

information providers such as the HCPC. Access to the internet as means of receiving information and conducting family life (as defined in the European Convention of Human Rights) is accepted as a norm by many of the UK population and has been the subject of a United Nations report (UN 2011). Increasingly the public, private and voluntary sector use their online portals as their main means of communication. The Office for National Statistics' review of UK internet use shows internet use increasing, however latest published results show 14 per cent of the adult population have never used the internet (ONS, Internet Access Quarterly Update, 2013 Q2). Furthermore individuals with a disability are approximately four times more likely to have never used the Internet than individuals without a disability. This means one third of disabled adults had not used the internet (about 3.8 million people), and disabled adults are over half (54 per cent) of the 7.1 million adults who had never used the Internet.

While this is a situation for national government to address all providers must ensure they communicate with all their audiences in appropriate ways.

Whistleblowing

There is high public awareness that things can go wrong in adult health and social care delivery from the publicity given to both the Winterbourne View and Staffordshire hospitals scandals, and to a less extent recent findings concerning residential homes run by Southern Cross. The role of whistle blowers in this field has greater recognition, and there are service user expectations that they will be 'looked out for' by professionals concerned about the practice of colleagues. Are the current standards robust enough to meet concerns of disabled people and carers?

An ageing population

Finally, the growing and ageing population is only going to increase pressures on social care systems. Three quarters of people aged 65 will need care and support in their later years (Department of Health). Only one third of men (33%) and 15% of women will never need social care (Care Quality Commission). The impact of the ageing population on health and social care services is hard to predict but the number of older people with care needs is expected to rise by more than 60 per cent in the next 20 years (Kings Fund, Time to Think Differently). With an increasing percentage of older people in our population, and a cohort of older people living longer there will be an increased demand for practitioners who currently come under HCPC regulation. A question for the HCPC is, do the standards need be framed or presented differently with this population in mind?

Methodology

In consultation with the HCPC, Shaping Our Lives created a questionnaire which enabled us to explore service users' response to the 14 existing standards and gather their thoughts on the content, format and accessibility of the standards. It should be noted that the participants were not given all the supporting text for each standard because this would have been too long to manage in an interview or focus group. However, the interviewers and facilitators had knowledge of the supporting text and prompts to guide participants to the key issues for each standard.

Between July and September 2013 Shaping Our Lives interviewed 31 individual service users, and held one focus group attended by adult service users. In addition two adults with learning disabilities were interviewed separately with their support worker. All interviewees were asked the same set of questions. The questionnaire is in Appendix Three. Following the interview feedback from two people with learning disabilities, Shaping Our Lives asked for a report on the accessibility of the existing standards from CHANGE www.changepeople.org, experts in the communication needs of adults with learning disabilities. Their report is shown in full in the Findings.

People who were interviewed were diverse in age (the youngest was under 18, the oldest 77), living in a variety of settings with the majority living independently, some with family, and a couple in supported accommodation. A handful (six) declared themselves as carers. Nearly 70 per cent were living with a long term condition or impairment. Shaping Our Lives interviewed more women than men (19 to 16). The ethnic profile of interviews was diverse. Interviewees were asked to self-classify; 17 people declared themselves as white, and 20 as either black, Afro-Caribbean, African, or Asian.

Between them the interviews had used all of the 16 professions required to register with HCPC:

Physiotherapists (nearly 60 per cent of respondents)

Occupational Therapists (over 50 per cent)

Radiographer (just over 50 per cent)

Social Workers in England, Biomedical and Clinical Scientists (all just over 40 per cent)

Dietitians, Hearing Aid Dispensers and Speech Therapists were the least used (by one or two people only).

(This is just a sample of the total 16 registered professions)

For a breakdown of responses to all quantitative questions see Appendix Four. Percentages, where reported, relate to the 31 interview

responses. We have provided quotes from interviewees throughout the report, to illustrate a common view or as a useful, if minority, opinion or experience. Although majority views are important and lend weight to a force of feeling on some issues, the lived experience of service users varies because of factors such as condition, care needs, personal circumstances and geography, so in reviewing the findings Shaping Our Lives has taken into account individual views and reported them.

In addition we asked the Words and Pictures team at CHANGE to look at each standard in terms of comprehension. Their response is shown boxed under each standard. The Words to Pictures team met for a full hour and a half session to discuss each of the standards. The Words to Pictures team was made up of eight people with learning disabilities.

Findings

As a general note many of the interviewees spoke from experience of services which are free at the point of delivery and were delivered within the framework of a local health or social care department (also found in The Focus Group research). As such they assumed that practitioners were governed and regulated by their employers.

‘I think they [the standards] would be hard to enforce in a private setting as these tend to be sole practitioners. Easier to enforce in an NHS setting.’

A handful had experience of buying their own services, and did then acknowledge that for small or sole practitioners, there must be a form of body which oversaw them.

Standard 1: You must act in the best interests of service users.

The service users agreed that their best interests were important. They had many individual comments on what their best interests were, with some common themes.

Listening to my needs

Dignity

Respect

Recognition of service user as expert in own care

‘Understanding that I am the best person that knows me, my capabilities and my body.’

Involving service user in decisions

Professionalism

Not discriminating (giving equal treatment to all)

Choice

Transparency and honesty about outcomes

People first, not problem

A couple of people expressed the important view that cost of treatment should not impact on the best interest decision. A couple of people in the focus group reminded us that professionals and service users do disagree about best interests particularly when what the service user wants is perceived to involve risk.

However this standard proved to be the hardest to get people to comment on initially. The question was met with long pauses, and several 'what does this standard mean?'

The Words and Pictures team said:

The group were divided about the meaning of this standard. Some of the group thought this could be about the things that you were interested in. Some of the group grasped what this was about. The term 'best interests' was misinterpreted by some of the group.

- "Is this about speaking up for somebody in a good way?"
- "Someone wants to help you and be kind to you."
- "Doing something that is best for me."
- "Doing something in the right way."
- "Is this about something you are interested in?"
- "Some people with learning disabilities won't know what this means."

Standard 2: You must respect the confidentiality of service users.

No interviewees disagreed with this standard. They were asked to explore what confidentiality meant in terms of who information might be shared with. All assumed information would be shared. Many answered it should be, but only on a need to know basis. Several respondents cited their GP as the most obvious person who would be given information about them, with other colleagues of the service provider also frequently mentioned.

Of the individual respondents 16 were not concerned about confidentiality, 11 were concerned but did not give any concrete examples of when breaches of confidentiality had happened to them. There were more concerns about the protection of information generally, and the accessibility of electronic information.

Some respondents thought it was a good thing that useful information could be shared with other parties such as other patients to help with their decision making, or students as study aids.

There were a couple of examples given of where carers and parents of adult service users were given information without consent. The focus group commented on permission to be asked before information is shared, with some in favour. Others pointed out that it could be detrimental to treatment if information was not shared.

The Words and Pictures team said:

Everyone in the group understood what this meant, but accepted that some people with learning disabilities might not understand terms like 'confidentiality' and 'respect'. Volunteers at CHANGE are fairly familiar with these terms due to the nature of the work we do.

- “Confidentiality means that you mustn’t tell anybody else what has been said – it has to be kept private.”
- “Is it about having your own privacy?”
- “It’s about not letting information leak out, keeping it to yourself.”
- “Confidentiality is a long word for some people with learning disabilities to understand – maybe private or privacy would be better.”

Standard 3: You must keep high standards of personal conduct.

We asked what personal conduct meant to the interviewees. There was a lot of overlap with Standard 1. The three most common responses for respondents describing a high standard of personal conduct were:

Respect (cited 9 times)

Integrity (cited 4 times)

Meeting my needs (treating me as an individual) - (cited 4 times)

Other attributes which contribute to a high standard of personal conduct are that the practitioner is:

Motivated

Caring

Puts my best interests first

Transparent in their dealings, discloses information to me

Polite, welcoming and friendly

Well presented – e.g. clean premises and personal appearance

Understands safeguarding.

When asked what they would do if they had a concern about the conduct of someone providing a service, several interviewees said they would simply take the matter up with the provider there and then. At the focus group there was a discussion about first going to speak to the practitioner’s manager rather than contacting the HCPC, as the latter was seen as a very serious course of action that may lead to someone being struck-off or suspended from practise. One person made a suggestion:

‘The client should be told how to complain at the initial visit.’

For the handful of interviewees who had experience of paying for services they had a pretty direct method of dealing with their concerns:

‘If private contractor would complain directly, as it is my money.’
And-

‘Could withdraw from service if I’m paying for it.’

Other interviewees, talking about public services, said they would go to the provider’s manager, with some mentioning a formal written complaint. One person mentioned PALS, and two the HCPC (although three other people said they would report it ‘to the appropriate [professional] body’).

The Words and Pictures team said:

Some of the group struggled with the term ‘personal conduct’ – this had to be explained using easier words. All the group knew what ‘high standards’ meant.

- “What does conduct mean? Is there an easier word for it?”
- “Does conduct mean to be fair and kind to people?”
- “Does conduct mean staying in touch with people?”
- “It makes me think about conducting electricity!”
- “I think this is about attitudes, behaviour and how to respect people.”

Standard 4: You must provide (to us and any other relevant regulators) any important information about your conduct and competence.

There was a discussion in the focus group on how the current stretched resources in social work departments can create an environment where conduct and competence are compromised with some feeling that this standard was not fit for purpose in all situations. There was a question as to what duty of care HCPC has to practitioners whose conduct and competence is challenged.

There was some cynicism in the focus group that asking practitioners to be self-regulating and inform on themselves was the best method to protect service users.

Most individual respondents had nothing to add to this standard but a handful wanted to be sure that it covered issues outside working life, such as any criminal conviction,

A couple of interviewees mentioned the role of other professionals in monitoring their colleagues.

‘Should have to provide information about themselves, and if necessary about other practitioners.’

The Words and Pictures team said:

There was a lot in this standard that the group didn’t understand or misinterpreted. The words ‘relevant regulators’, ‘conduct’ and ‘competence’ were hard for most of the group to read and understand.

- “This is not an easy standard to understand, there are a lot of difficult and jargon words used.
- “For me ‘competence’ means how you act and ‘conduct’ is about respecting other people.”
- “This would have to be written in a more accessible way for me to understand what this means, with less jargon.”

Standard 5: You must keep your professional knowledge and skills up to date.

We wanted to know how this standard can be monitored by service users and asked interviewees how they would check that a service provider is giving the latest and best treatments. For several respondents their answer was to look on the internet and educate themselves about latest treatments before going to their appointment. A couple of respondents were confident about their own knowledge, having had their condition since birth.

A handful of respondents cited professionals displaying up to date certificates. Others assumed that there was some process of continual professional development monitored by the HCPC which was connected to registration. Or that the HCPC proactively checked registrants’ qualifications, assuming it was the regulator’s job to keep track of individual registrants.

‘Would check out for myself what most up to date treatment is. Would assume legislation and their professional body keeping them up to date.’

Others were more puzzled as to how they would go about this.

I don't know! Look on the internet?

The Words and Pictures team said:

The term 'professional knowledge' was discussed a lot. Some the group understood what this meant and some didn't.

- "What does 'professional knowledge' mean?"
- "'Professional knowledge' is about what you're good at in your job."
- "I think this standard is about keeping your training skills updated."

Standard 6: You must act within the limits of your knowledge, skills and experience and, if necessary, refer the matter to another practitioner.

The problem with this standard, expressed by some service users, is that it implies that the service user does not get a choice in whom they are referred to. There was also scepticism, based on personal experience, about how much choice one could be offered within the framework of both geography and cuts to budgets.

'Generally just referred on to someone else, especially in health service. Would expect to have a choice, but geography means that choice is not always available.'

We explored what support or information interviews would need to help them make an informed choice if this happened.

Respondents listed several decision making tools:

- Access to a register of other providers listing their skills and experience.
- To be involved in the decision.
- Trusting reviews from other service users (friends, relations).
- Trusting the judgement of the original provider.

'Expect practitioner to have full knowledge of my condition so they can make proper enquiries on my behalf, and refer me to right person'

The Words and Pictures team said:
 This standard was hard for the majority of the group to understand. The terms 'limits of your knowledge' and 'practitioner' caused some confusion. Only one member of the group said he understood what this was about.

- "I don't know what this means. 'Practitioner' is jargon to me; this would have to be explained."
- "Is this about acting within your limits?"
- "This standard is quite long and uses a lot of jargon words. I don't think many people with learning disabilities would know what it meant."

Standard 7: You must communicate properly and effectively with service users and other practitioners.

We asked what was important about communication for the interviewees. A common theme was provision of information in a way that suited the service user.

'That they communicate appropriately to the person who needs information e.g. language skills, or large print. The practitioner should know to take communication needs into account.'

Several respondents gave examples of different ways of making sure information was accessible such as large print and easy read.

Several respondents mentioned the additional needs of some disabled people to ensure good communication, with the emphasis on the practitioner having disability awareness.

'If a patient has additional needs in any shape or form, they need to be given time to communicate. Might need easy read or an advocate. The practitioner should welcome that, not be prejudiced.'

'Making sure that practitioner understands what to expect from a disabled person on the first visit e.g. be patient, understand the limitations caused by the disability.'

The Equality Act was mentioned as the framework within which communication to service users should be judged. This is because the law covers the provision of goods and services.

One interviewee felt that one of the standards (they did not specify which one) should reference the environment that services are provided in, and specify that the environment had to be accessible to the service user.

The Words and Pictures team said

The majority of the group understood what this standard was about, but there was a lot of discussion about how it could be written more accessibly. Again the term 'practitioners' caused some confusion.

- "This is about how you work with other people."
- "It's about communicating with other people, and how you should do this in a clear way."
- "I don't understand what the term 'practitioners' means".
- "There could be better words than 'effectively' and 'properly', I'm not sure what these mean in this sentence. Maybe communicate 'clearly' would be better".
- "Could you say 'other people you work with' instead of 'other practitioners?'"

Standard 8: You must effectively supervise tasks that you have asked other people to carry out.

When asked who they think is responsible if someone else is asked to do a task, the majority of respondents initially indicated the person making the request, referring to them as a manager or supervisor. Some said both people would be responsible. However there were questions asked about the supervisory experience of some practitioners, and whether in fact supervise was the correct terminology. How could a practitioner supervise someone if they were not trained, or indeed not from the same discipline? This point was also raised in The Focus Group research.

A couple said it was the responsibility of the referee to make sure the second party had the right skills and experience but not necessarily supervise them.

'Responsibility for is a better word than supervised.'

The Words and Pictures team said

Most of the group loosely understood what this meant. Some people struggled with the words 'effectively' and 'supervise'. Some of the group knew what supervise meant through their experience of supervision at CHANGE or on jobs they had done in the past; however, they said not all people with learning disabilities would know what supervise meant.

- "Being supervised means being told what to do."
- "'Supervised' means someone that's your boss."
- "I was supervised in my old job at B&Q. For me this standard is about being the person that is in charge of watching over the team and checking that things have been done professionally, and you've got to say how the people got on."

Standard 9: You must get informed consent to provide care or services (so far as possible).

We wanted to find out what service users thought this meant, and to unpick what is understood by informed consent. All respondents apart from one were confident they understood the concept of informed consent, and what that meant for them. There were various definitions given:

'It means that they must get my consent, even if my consent is different from those around me, it is for me personally to say what I want.'

Practitioner should have gone through all the options, even procedures that they cannot deliver, and shared this with me.

'No good recognising the words, have to understand the meaning and the implication.'

'That we are fully involved in our treatment. We understand what is happening and have the chance to refuse.'

There was some discussion about mental capacity and meaningful consent, and also how informed consent could be applied in an emergency situation.

The Words and Pictures team said
 Around half the group were confident that they knew what this standard meant. The concept of 'informed consent' is familiar to some of the group, due to consent forms that some of them have had to sign in the past to do with photographs and videos used on CHANGE's website/social media.

- "I'm not too sure what the word 'provide' means in this standard."
- "Consent is about signing something. Does it mean that you have to sign a form?"
- "It is about signing a document to say that you give your permission to do something?"
- "I think the word 'permission' would be better than 'informed consent'".

Standard 10: You must keep accurate records.

When asked how important it was to them that accurate records were kept, 67 per cent of respondents said it was extremely important and 27 per cent very important.

Most interviewees said that they would check that their records are accurate by asking to see them. Some talked about being copied into letters between hospital based staff and their GP. One gave a helpful suggestion about having a check list for practitioners of what information should be included on all notes. Another gave an example of being asked to sign and date notes at the end of an appointment.

When asked 'Would you want to see your own records?' most respondents said yes. A handful (four people) said no, and three said yes but gave reasons why seeing their own records would not be straightforward.

'There could be distressing information in the records but all records should be shared.'

'Although I have been reticent to ask recently in case I am viewed as a difficult patient.'

'Not unless I had a concern about practitioner and accuracy of records.'

The Words and Pictures team said

About half the group was unsure what the word 'accurate' meant.

- "This is about keeping something in a file, like your birth certificate."
- "I think this is about keeping something written up to date – a bit like our supervision notes."
- "'Accurate records' means records that are correct. Maybe the word 'accurate' could be replaced with a more accessible word, or explained in a different way."

Standard 11: You must deal fairly and safely with the risks of infection.

No respondents disagreed with this standard; some pointed out how it protected therapists, the service user and then other service users. When we asked service users how they thought the risk of infection should be dealt with there was a great deal of awareness about measures in health environments - most came up with very practical solutions, which were mainly health care related. For example:

'The same way as any health care professional e.g. using gloves, washing hands before and after, making sure equipment is autoclaved, using fresh equipment where appropriate, throwing old equipment away, using new instruments for each patient.'

Some service users wanted transparency about the risks of infection in a particular environment so they could make a decision about using a service. A couple of interviewees reminded us of the onus on service users to declare their infections.

One member of the focus group reminded us that this standard had to apply to practitioners that visited people in their own home. One interviewee pointed out that in managing infection risks practitioners should ensure basic hygiene measures, such as antibacterial gel dispensers, were accessible to all service users.

The Words and Pictures team said

Most of the group had an understanding about what this standard is about. The word 'fairly' confused a few people. Most of the group knew this was health related.

- "This is about washing your hands and your body and making sure you are clean."
- "This could be about using those special sprays so you don't pass on any germs or infection. Infections make you poorly."
- "This standard is about keeping safe and looking after yourself."

Standard 12: You must limit your work or stop practising if your performance or judgement is affected by your health.

The vast majority (90 per cent) agreed with this standard. Additional comments suggested a regular review over a certain age (as with driving licence renewals) or a mandatory retirement age. One respondent reminded us that lifestyle choices had as much impact as health on performance. One commented that unhealthy practitioners were bad role models.

Others looked at the issue from the point of view of practitioners who could be disabled people. They were concerned that practitioners were supported to return to work, one giving the specific example of a practitioner with mental health problems (a fluctuating condition). Another was concerned with practitioner confidentiality:

'I think need to respect that practitioners don't have to disclose. They are allowed to keep their health condition confidential.'

Three people didn't agree with the standard. One of those said:

'I don't think practitioners should be forced to stop because of a health condition. Reasonable adjustments should be made. Can deprive patients of that lived experience of that condition/impairment which might be useful.'

Someone else agreed with the standard, but made the same point

'Yes, but this is not cut and dried, depends on how performance is affected. E.g. Visually impaired people who are physios.'

Two people pointed out problems with self-assessment

‘Self-assessment is not an accurate benchmark. The pressure to continue would override - needs independent judgement. Self-assessment for a sole practitioner – [disclosure] could threaten the therapist’s livelihood.’

‘Important for professional to recognise a problem, maybe cut down on work. Might need to make decision for them if they are making mistakes.’

It was noted that the standard was all about stopping work, but not enabling a practitioner to come back to work.

The Words and Pictures team said

Some of the group struggled with the concept of this standard and found it hard to relate to. A few of the words in this standard confused people – particularly: ‘practicing’, ‘performance’ and ‘judgement’

- “Does practising mean like a doctor or GP?”
- “For me the words ‘performance’ and ‘judgement’ are jargon. Could there be easier words or an easier way of saying it?”
- “Does judgement mean when you are diagnosed?”

Standard 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.

Everybody bar one interviewee agreed with this standard and most respondents had nothing further to add. Additional comments people did make related to the importance of being able to trust a professional provider and have confidence in them. Someone reflected it is difficult to separate professional from personal life, so does the standard cover both?

Someone else related this treatment quite specifically, rather than a general characteristic:

‘Important to behave like this to ensure confidence of patient. Being up front (honest) even if it is bad news. Best not to hide things.’

One interviewee felt that this was the standard which related most to whistle blowing, and providing protection for the practitioner accordingly.

It was important to note that ‘honesty’ and ‘integrity’ were both qualities listed in response to what was in a service user’s best interests (standard 1) and elements of appropriate personal conduct (standard 3).

The Words and Pictures team said

Again, there were a few words in this sentence which the Words to Pictures team didn’t understand – in particular ‘integrity’.

- “Is this about doing something that damages your image?”
- “I don’t know what ‘integrity’ means, could there be an easier word used?”
- “This is about how you speak to people, I don’t want to offend anyone, so I look for a different way to say things so I don’t damage things for people. I try to be honest.”

Standard 14: You must make sure that any advertising you do is accurate.

Interviewers were asked about what they thought was important when a therapist is advertising a product or service. This gave them the opportunity to expand upon the concept of accuracy and phrases such as honesty, transparency, truthfulness were used, as well as making it clear an alternative product is available.

‘I think it is important that they make sure service users know that service/products may or may not be necessary.’

‘The language/wording should not be medicalised – the language used should be plain English.’

There was a sense of this standard stating the obvious, in that any practitioner advertising inaccurately would be doing something very wrong.

The Words and Pictures team said

Everyone in the group understood this standard. However, a couple of members were unsure what ‘accurate’ meant.

- “It’s about marketing or selling something in a correct way.”
- “Everyone knows what advertising is.”

Knowledge of standards and the HCPC

The majority of interviewees, 60 per cent, had not heard of the standards. Only 30 per cent would have known where to find them (although once the HCPC had been introduced many assumed there would be a website they could find the standards on). Most interviewees, 83 per cent, did not know that the HCPC had a Register of practitioners, although a couple remembered seeing the HCPC referred to on individual therapist's business cards/flyers. Other respondents assumed the practitioners they saw had some sort of regulatory body, even though they could not name it.

The relevance of the standards to all professions

We asked the interviewees if they thought that all these professions can be covered by one set of standards.

70 per cent of individual respondents said that one set of standards could cover all 16 professions.

Some qualifying remarks were made, however, on the lines of having some specific additional standards for individual professions or that not all standards would apply to all professions.

'To a large extent yes [covered by one set], but suspect they would need tweaking for some of the professions. Lots of standards are common across most professions but others specific.'

'Most of these therapists have boards that look at the specifics of that profession.'

The focus group respondents were less convinced than the individual respondents that all the professions can be covered by one set; only two people thought they could with the other six saying no. No actual reasons were given apart from one respondent stating they thought social workers were an exception and should have a different set of standards.

One interviewee reflected on the changing climate of provision:

'Atos and Capita are using health practitioners to do assessments. Do these standards apply to those practitioners? Should there be additional standards that apply if working as a sub-contractor outside the NHS?'

Content, Format and Accessibility

There were quite a lot of comments about the language that the standards were written in being a bit challenging, with a simple plea from one interviewee to make them user friendly.

The Word and Picture team comments (in boxes) are very pertinent when considering use of language and how it impacts on the accessibility of the standards for all service users.

One interviewee neatly summarised the comments of several respondents:

‘The thing I don’t like about them is that some are relevant to a member of the public or patient and some are relevant to the therapist or professional or the organisation they work for and they’re all bundled together in no particular order. Do people think there might be value in having 5 or 10 relevant to the patient and 5 or 10 relevant to the professional - and then separated in some way?’

Prior to the commencement of the research, Shaping Our Lives raised the point that some standards were more relevant to the professional than to people using a service. As a result, it was agreed that less time would be spent discussing and evaluating 2 of the standards and the interview questions were less detailed accordingly. These were:

Standard 4 states: You must provide (to the HCPC and any other relevant regulators) any important information about your conduct and competence.

Is there anything you would like to add to this?

Standard 13 states: 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.

- i) Do you agree with this? Yes/No
- ii) Is there anything you would like to add?

The respondents did not make many comments on either standard, reflecting the assumption by Shaping Our Lives that these were less relevant to people using the services.

In summary, it is suggested that 2 sets of standards would be more appropriate. One that sets out the required standards of conduct, performance and ethics for professionals registered with the HCPC. These would be linked to a second set or 'charter' for people using services and would outline what they should expect from a professional.

In some cases the standards were misinterpreted by participants and further guidance was needed to clarify the meaning. Although the supporting text achieves this, more concise standards with short supporting bullet points and accessible language would be preferred.

Participants felt that some of the issues covered in the standards were also met by legislation such as the Equality Act 2010. For example, in the focus group participants commented that accessible premises and communication would be expected as part of the provision of goods and services guidelines.

Several people wanted the HCPC to ensure that all documents that it produces for the public (and practitioners who have access needs) are available in all formats, at the point of service as well as online. Video was also mentioned as a format that is useful.

For people who had checked out the HCPC online (as part of their interview) several reported finding it difficult to locate the standards on the HCPC website.

Conclusions

Overall service users were less interested in the number of, content or wording of the standards as they were in relating how their lived experience reflected the implementation of the standards and whether they guided the practices that they encountered.

A common theme from lived experience was encountering practitioners who had low disability awareness or understanding of disability equality. This was particularly mentioned in relation to communication and provision of accessible premises, but also touched on in relation to the perceived capacity for understanding of some disabled people.

Quite often interviewees would raise issues when discussing a particular standard which are addressed by the HCPC in their commentary on each standard or in other documents on the HCPC website. However these are not immediately accessible to service users.

Understanding existing standards

Most standards were generally understood when reviewed by our 30 interviewees and focus group, and some of them were understood by the Words and Pictures group, but not all. It should be noted that understanding by the respondents had been improved by the rewriting and simplification, in some instances, of the standards by Shaping Our Lives when writing the questionnaire. This understanding was also enhanced from prompts for interviewers and facilitators.

Standard 1 was the standard that most respondents had the least comprehension of; the most common response was a stab at what best interests meant. Given the best interest examples were so diverse the question we asked was to how a standard could meaningfully address best interests. The common theme that emerged was about respect, understanding and behaviours. This standard could be rewritten to provide a useful code of conduct; and consideration given to merging it with standard 3.

Adults with learning disabilities found the standards or the concepts within them more difficult to understand. It was noted by some interviewees from all cohorts that some of the concepts were a bit obtuse.

Relevance of the standards

While nobody questioned the relevance of any standard based on their experience of the health and care system there were some questions about the aspirational nature of some standards when health and care services have to be delivered in real time, with limited resources available. The two standards which were most questioned in this context were standard 6 (referral options) and standard 8 (effective supervision). The only standard which attracted any general comments about relevance was standard 14 because **a)** such matters are covered by another regulator (the Advertising Standards Authority) and **b)** advertising accurately is an example of behaving with honesty and integrity and therefore is covered by at least two other standards.

Service user focus

Given the profile of our respondents, it is not surprising that user involvement, disability awareness and accessibility were recurring themes across the standards. Respondents were answering based on their lived experience of being excluded from decisions about their care, not recognised as experts in their own care and finding services inaccessible to them because of their impairment or condition. It is important that the HCPC recognise the importance of the view through the lens of our service users and their carers.

Additions to the standards

There were no new standards recommended but several suggestions about how individual standards could be improved either by increasing clarity or adding to what was included. These are referenced in the Findings. Although the research was not tasked with examining the structure and appropriateness of the standards as a tool for both professionals and people who use services, they were comments and doubts that they all worked to meet everyone's requirements. It was suggested that some standards only applied to one or other of these groups.

Awareness of the HCPC

There was low awareness among service users and carers of the existence of the standards and their purpose, and of the HCPC as a regulatory body. Respondents had some concerns about how they should use the standards and the system for raising a complaint. Low awareness of the HCPC's existence and role means a route for satisfactory resolution of a problem is not there.

Recommendations

Shaping Our Lives is making these recommendations from the service user and carer perspective to feed into the HCPC review of standards taking place in 2014. These recommendations are a response to the conclusions we have drawn from our findings, and also taken from the thoughtful suggestions made by respondents.

Our overarching recommendation is that in writing the new standards, the HCPC should consider differentiating between which standards relate to the conduct and performance of practitioners within their profession, and those which relate to the conduct of the practitioner in relation to people who use their services, grouping them accordingly.

To accompany the new standards the HCPC should consider publishing a simple check list which provides for service users as customers – a charter of what should/should not happen. This document could be displayed at point of delivery where feasible (we recognise this is not always possible e.g. with paramedics).

We have grouped our other recommendations under five themes, although they do interrelate;

- Being in control
- Integration and joint working
- Accessibility
- Considering equality
- Protection of interests

Being in control

The concept of no decision about us, without us has been a central tenet of the disability movement for many years and is now part of the legislative framework which governs health and social care. Our recommendations are:-

- That the standards are explicit about respecting users as people, valuing them as experts in their own care with the right to make choices about health and social care.
- The standards need to set out good practice in relation to full user involvement in their care and treatment, including access to records; awareness training for all staff; the meeting of needs identified at assessment, with particular attention to people with multiple needs.

- The future process of developing, implementing and monitoring the standards should include full and ongoing user involvement to ensure the maximum effectiveness of the standards and HCPC's role in regulation.

Integration and joint working

- In recognition that integrated services and joint working between professionals gives good outcomes for service users the new standards should reflect and enable this way of working.

Accessibility

These recommendations are for the benefit of service users and practitioners, in recognition that the latter can be excluded by access issues too. Accessibility includes buildings, information provision, attitudes and behaviours.

- The standards should specifically set out what is unacceptable in terms of disability equality and discrimination in the provision of goods and services.
- When writing the new standards the HCPC should use concepts and language that are accessible to practitioners and people using the services.
- When looking at accessibility the HCPC should consider:
 - How easily the public can find the standards and other policies and procedures.
 - Making the standards available at the point of service.
 - What formats the standards (and other documents) are provided in.
 - that information is provided online and offline.
- To take into account that alternative forms and formats of communication are vital for some disabled people in order to access services and information.
- To provide accessible information online and offline.

We note that the HCPC has some documents (available online) already in Easy Read and we would encourage the production of Easy Read

versions of all HCPC documentation, as well as providing documents in Word and PDF files, and as BSL videos.

Although this is beyond the scope of the research, we would urge the HCPC to ensure disability awareness and equality training are part of a practitioner's continuing professional development, and, if is not already a condition of registration, to ensure new registrants have had such training.

Protecting services users

Protection includes confidentiality, safeguarding, complaints procedures and actively addressing concerns about practice and behaviours. We recommend:

- That the review of standards concerning information and confidentiality takes account of the increasing use of both electronic communication and storage and the use of portable and mobile devices, recognising both the benefits to service users with different access needs and the consequences to protecting confidentiality.
- To ensure the new standards are explicit about the whistle blowing role of practitioners in protecting vulnerable service users.
- Clarity about what the standards are for and how they can be useful to service users is needed and documentation resulting from a review of this aspect should be readily available to service users.
- That the HCPC promotes itself more widely as a regulatory authority.
- That the HCPC promotes its complaints procedure more widely, with clarity about who to complain to and how.

Healthwatch England has launched a new online tool for people wishing to raise a complaint about a health service and this may present an opportunity to signpost people on action they should take.

Appendices

References

Health and Social Care Act 2012: fact sheets, [link to documents online](#)

'State of Care' report, Care Quality Commission 23 November 2012
[Link to report online](#)

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Appendix One

Health and Care Professions Council Your duties as a registrant

The standards of conduct, performance and ethics you must keep to:

1. You must act in the best interests of service users.
2. You must respect the confidentiality of service users.
3. You must keep high standards of personal conduct.
4. You must provide (to us and any other relevant regulators) any important information about your conduct and competence.
5. You must keep your professional knowledge and skills up to date.
6. You must act within the limits of your knowledge, skills and experience and, if necessary, refer the matter to another practitioner.
7. You must communicate properly and effectively with service users and other practitioners.
8. You must 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).
10. You must keep accurate records.
11. You must deal fairly and safely with the risks of infection.
12. You must limit your work or stop practising if your performance or judgement is affected by your health.
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.
14. You must make sure that any advertising you do is accurate.

Appendix Two

List of registrants

	Service
A	Arts therapists (art, music and drama therapists) - encourage people to express their feelings and emotions through art, such as painting and drawing, music or drama.
B	Biomedical scientists - analyse specimens from patients to provide data to help doctors diagnose and treat disease.
C	Chiropodists and podiatrists - diagnose and treat disorders, diseases and deformities of the feet.
D	Clinical scientists - oversee specialist tests for diagnosing and managing disease. They advise doctors on tests and interpreting data and carry out research to understand diseases.
E	Dietitians (dieticians) - use the science of nutrition to devise eating plans for patients to treat medical conditions. They promote good health by helping to facilitate a positive change in food choices.
F	Hearing aid dispensers - work in private practice to assess, fit and provide aftercare for hearing aids.
G	Occupational therapists - use specific activities to limit the effects of disability and promote independence in all aspects of daily life.
H	Operating department practitioners - participate in the assessment of the patient prior to surgery and provide individualised care.
I	Orthoptists - specialise in diagnosing and treating visual problems involving eye movement and alignment.
J	Paramedic - provide specialist care and treatment to patients who are either acutely ill or injured. They can administer a range of drugs and carry out certain surgical techniques.
K	Physiotherapists - deal with human function and movement and help people to achieve their full physical potential. They use physical approaches to promote, maintain and restore wellbeing.
L	Practitioner psychologists - attempt to understand the role of mental functions in individual and social behaviour.
M	Prosthetists and orthotists - supply prostheses and orthoses to patients. A prosthesis is a device that replaces a missing body part. An orthosis is fitted to an existing body part.
N	Radiographers - plan and deliver treatment using radiation. Diagnostic radiographers produce and interpret high-quality images of the body to diagnose injuries and diseases.
O	Social workers in England - promote social change, problem solving in human relationships and the empowerment and liberation of people to enhance well-being.
P	Speech and language therapists - assess, treat and help to prevent speech, language and swallowing difficulties.

Appendix Three

Profile monitoring questions

1. Gender: please type F or M

2. Age:
Which of the following age groups do you belong to? (please highlight age band or state age)
Under 18 18 – 24 25 – 34 35 – 44 45 – 54
55 – 64 65 or over Prefer not to answer

3. Ethnic group (as you would describe yourself)

4. Are you a:

Service user (as in one or more of the services listed below)?	
Do you have a long term health condition or impairment (Disabled person)?	
It would help us if you could briefly state the nature of your condition or impairment	
Carer?	
If a carer, are you caring for someone under 16 years of age?	

I

5. Living arrangement:

Living independently
Living with family (because their support is required)
Supported accommodation
Residential care
Other (please state)

6. Have you used any of the services covered by HCPC?

Survey Questions

Standard 1 states: The provider must act in the best interests of people who use their services.

Q7. This is a question about values. Thinking about your best interests, what would be important to you when using a service?

Standard 2 states: The provider must respect the confidentiality of people who use their service.

Q8.i) Who do you think information might be shared with?

ii) Do you have any concerns about confidentiality?

Standard 3 states: The provider must keep high standards of personal conduct.

Q9 i) In terms of personal conduct, what would you expect from a service provider?

ii) What would you do if you had a concern about the conduct of someone providing a service?

Standard 4 states: The provider must provide (to the HCPC and any other relevant regulators) any important information about their conduct and competence.

Q10. Is there anything you would like to add to this standard?

Standard 5 states: The provider must keep their professional knowledge and skills up to date.

Q11. How would you check that a service provider is giving the latest and best treatments?

Standard 6 states: The provider must act within the limits of their knowledge, skills and experience and, if necessary, refer the matter to another practitioner (service provider).

Q12. What support or information would you need to help you make an informed choice if you were referred to another practitioner by your provider?

Standard 7 states: The provider must communicate properly and effectively with people who use their services and other service providers.

Q13. What is important about communication for you?

Standard 8 states: The provider must effectively supervise tasks that they have asked other people to carry out.

Q14. Who do you think is responsible if someone else is asked to do a task?

Standard 9 states: The provider must get informed consent to provide care or services (as far as possible).

Q15 What do you think this means?

Standard 10 states: The provider must keep accurate records.

Q16. i) Rank how important this is to you (scale: extremely important to not at all)

i) How do you know your records are accurate?

ii) Would you want to see your own records? Yes/No

Standard 11 states: The provider must deal fairly and safely with the risks of infection.

Q17. How do you think the risk of infection should be managed?

Standard 12 states: The provider must limit their work or stop practising if their performance or judgement is affected by their health.

Q18. i) Do you agree with this? Yes/No

ii) Is there anything you would like to add?

Standard 13 states: The provider must behave with honesty and integrity and make sure that their behaviour does not damage the public's confidence in them or their profession.

Q19 i) Do you agree with this? Yes/No

ii) Is there anything you would like to add?

Standard 14 states: The provider must make sure that any advertising they do is accurate.

Q 20. What do you think is important when a service provider advertises a service or a product they sell?

These remaining questions are generals one about the HCPC standards.

21. Did you know these standards existed? Yes/No

22. Do you know where to find the standards? Yes/No

23. Do you know that the HCPC has a Register of service providers that work to these standards? Yes/No

24. Do you think all these professions (the 16 services listed) can be covered by one set of standards? Yes/No

25. Are there any changes or improvements you would suggest to these standards?

- Content
- Format
- Accessibility

Are the standards all relevant to you? Are some not important to people who use services? How should they be made available and in what formats? Should they be organised under sub-headings

Appendix Four

16. Standard 10						How important is this standard to you?		Would you want to see your own records?	
	Extremely	Very	Quite	Not very	Not at all	Yes	No		
Totals	20	8	0	0	0	26	4		
%	67%	27%	0%	0%	0%	87%	13%		

18. Standard 12		19. Standard 13	
Do you agree with this standard		Do you agree with this standard	
	Yes	No	
Totals	27	3	29
%	90%	10%	97%

21. Did you know these standards exist?		22. Do you know where to find these standards?		23. Do you know that the HCPC has a register of service providers that work to these standards?		24. Do you think all these professions can be covered by one set of standards?		
	Yes	No	Yes	No	Yes	No	Yes	No
Totals	12	18	9	21	5	25	21	8
%	40%	60%	30%	70%	17%	83%	70%	27%