



# **The Professional Standards Authority for Health and Social Care**

*Research with patients and service users on assuring the quality of health and care professionals through Right-touch regulation*

## **Qualitative research report July 2015**

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## 1. BACKGROUND

The Professional Standards Authority (PSA) **promotes the health, safety and wellbeing of patients, users of health and care services and the public** by raising standards of regulation and voluntary registration of people working in health and care. They are an independent body, accountable to the UK Parliament.

The PSA **oversees nine health and care professional regulators** and reports annually to Parliament on their performance. These regulators cover social workers, as well as professions, such as nursing and osteopathy.

The PSA also **accredits voluntary health and care occupational registers** to improve consumer protection and raise standards. These registers cover a broad range of occupations, such as psychotherapy and hypnotherapy.

In addition, the PSA: **conducts research and advises the four UK governments on improvements in regulation; promotes right-touch regulation** and publishes papers on regulatory policy and practice; and organises conferences and seminars to promote dialogue and debate.

The PSA published its guidance document, Right-touch regulation, in 2010. This sets out that regulation should only be used where patients or service users may in some way be harmed by the behaviour or actions of the people delivering care. As part of its review of the guidance document, the PSA commissioned qualitative research to explore how patients and service users perceive harm and what types of oversight are appropriate for various professions and occupations in the field of health and care. This report describes the findings.

## 2. RESEARCH OBJECTIVES

Overall, to gain the perspective of users of health and care services on certain key concepts:

- **What constitutes potential harm** in the eyes of users of health and care services?
- **How should various professions and occupations be overseen** to mitigate these potential harms?
- **What kind of oversight service users expect to be in place** for certain types of profession and occupations?
- **What evidence service users themselves might contribute** to, and how they might be involved in, decision-making about the appropriate type of oversight for the various professions and occupations?

In addition, the PSA also wished to explore **what type of information service users would like to access in order to understand different types of regulation** and other methods of overseeing professions and occupations.

### **3. METHOD AND SAMPLE**

#### **3.1 Method**

**A deliberative workshop approach was adopted.** Deliberative techniques are used when researching topics that target audiences may know little about. From experience, we knew that participants were likely to know very little about regulation and that it is a topic few think about, particularly in relation to health and social care.

Research practice is to ask participants for their spontaneous response to any question, based on their understanding or perceptions of a topic. Typically, prompts are then used to probe participants' views in more detail. A deliberative approach uses a succession of stimulus materials as prompts, which broaden and deepen perspectives on the topic. As stimulus is introduced, a more sophisticated discussion develops. The topic guide describes how the discussions unfolded and is appended at the rear of this report.

**3 x qualitative workshop discussions (duration 2 hours)** were conducted. The extended group length ensured that there was sufficient time to introduce different pieces of stimulus and discuss each at length.

### 3.2 Sample

The sample comprised 24 patients with long-term conditions using a wide range of health and care services. The sample was segmented into workshop groups (8 participants in each) which were split by age and lifestage, as follows:

- Workshop 1: male/female, BC1C2, 18-30 years old
- Workshop 2: male/female, BC1C2, 31-55 years old
- Workshop 3: male/female, BC1C2, 56-75 years old

Given the huge range of health and care professions overseen by the PSA, it was impossible to represent all professions within 3 workshops. However, a wide range of health and care professionals were represented across the 3 workshops, as described below:

Workshop	Date	Location (urban/rural)	Recent services used (across group)
Male/female BC1C2 18 – 30 years old	Tuesday 24 <sup>th</sup> March	Old Sodbury (near Bristol)	Pharmacist, GP, dentist, optician, hospital nurse, hospital doctor, paramedic, dietician, chiropractor, sports therapist, counsellor, hypnotherapist
Male/female BC1C2 31 - 55 years old	Monday 23rd March	St Albans	Pharmacist, GP, hospital, NHS 111, urgent care, gynaecology, 999, out of hours, CBT, hypnotherapy, counselling, colonic hydrotherapy, treatment from a diabetic nurse, dietician, chiropractor, X ray, acupuncture, physiotherapy, MRI scan, CT scan, reflexology
Male/female BC1C2 56 - 75 years old	Tuesday 24 <sup>th</sup> March	Cardiff	Pharmacist, GP, dentist, optician, hospital nurse, hospital doctor, dietician, radiographer, chiropractor, physiotherapist, osteopath, counsellor, psychologist, psychotherapist

#### 4. MANAGEMENT SUMMARY

Perceptions of harm were immediately and spontaneously linked to examples of physical harm. Participants clearly found it easier to entertain the idea of harm resulting from overall care or service inadequacies and were more reticent to blame individual practitioners.

When prompted to consider the harm that could arise in a wider range of settings, a wider range of types of harm emerged, including potential harm to vulnerable people using care services, potential harm to those using mental health services, complementary care services and those accessing services in independent settings. Participants realised that harm could arise from decisions made in non-clinical settings (via decisions made by NHS managers, for example).

Older people using care services, young people and people with disabilities were identified as particularly vulnerable to harm. Equally, when feeling poorly and using health and care services, all of us were considered vulnerable and reliant on the skill and experience of health and care professionals.

When prompted with a range of examples, two broad categories of harm emerged. Physical and mental harm were felt to result from two broad categories of health and care professional behaviour: 'criminal' and 'unethical'. Physical harm was more likely to be described as the result of 'criminal' behaviour than mental harm which was more likely to be described as the result of 'unethical' behaviour. General poor practice (such as failing to adhere to cross-infection control protocols, or misdiagnosis through carelessness) was less of a focal point among the majority of participants.

When prompted, participants were able to identify examples of less visible harm. It became apparent that these types of harm would only become visible more widely if the injured party made a complaint or an insurance claim. In this context, the importance of feedback became obvious. Participants were also able to identify that there can be long term consequences from subtle harm (i.e. knock on effects) than might impact upon an

individual's life in ways that are hard to link back to a care-related incident. These types of subtle harms are also important to take into account.

To motivate more people to offer feedback, participants suggested that: feedback channels would need to be publicised; feedback mechanisms would need to be fast, clear and convenient; and that organisations would need to demonstrate that they have acted on feedback to improve services.

Assumptions about which professions were regulated and which were not were based on: the potential to cause harm (perceived to be highest amongst traditional clinical practitioners and lowest amongst complementary practitioners) and the setting in which practitioners were practising. Health professions such as doctors and nurses were perceived as more 'traditional' occupations that would operate within the more traditional settings (for example, within a hospital). There was an assumption that hospital and care home settings were regulated, and that independent and in-home settings were less likely to be regulated.

Participants were not so interested in becoming involved with the regulator – however, even though they needed prompting, the subtle/indirect methods of maintaining high standards were felt to be just as important.

The appetite to become an 'expert by experience' was highest in the 56-75 year old group and was driven by ongoing interest in niche conditions (e.g. lifelong skin condition) and supporting services to provide quality care for users with similar conditions. It seems likely that 'experts by experience' would be more motivated to support the development of niche areas of regulation e.g. a particular type of nursing rather than nursing in general. They would also need to understand how their involvement would benefit services - and ultimately patients.

Overall, participants wanted a regulatory approach which included the following elements: ongoing processes to ensure that fully qualified professionals are maintaining fitness to practise standards and sanctions for those who are proved to be unfit to practise. A

voluntary register was considered appropriate for those practising in non-traditional professions, as long as it was supported by a kite mark system.

Alerting participants to the complexities of regulation created an appetite to know more about it. In future, a single source of information explaining the regulatory structures for different professions would be valued.

## 5. MAIN FINDINGS

### 5.1 The concept of regulation

**It was only the 31-55 year old age group who had a relatively good working knowledge of how regulation works, due to their experience of regulation via employment:**

- **They understood the difference in role between regulators and government:**  
*“Government is more high level, the regulator is more specific to the area they’re regulating so they should be more in touch with doctors and the decisions they’re making.” “Government should be overseeing the regulators.”*
- **They were also able to talk about regulatory mechanisms** e.g. investigation to make sure an untoward incident does not reoccur, learning derived from the investigation – and possibly sanctions for the individual involved e.g. taken off a register.
- **They were also able to discuss how systems could contribute to the prevention of harm** e.g. audits, checklists, procedures, policies and management systems.

However, even this more knowledgeable group were not entirely clear about certain aspects of regulation, e.g. the role of professional bodies in contributing to the regulation of health professionals and the different types of regulatory systems, e.g. compulsory vs voluntary.

**For both the younger and older groups (18-30 and 56-75 years old), the concept of regulation was much less clear.** They talked in general terms about regulators ‘overseeing/supervising’, ‘licensing’ and providing standards for practitioners, but in practice it was not clear how oversight/supervision or licensing was achieved or standards monitored. They were also unclear about how different organisations contributed to regulation more generally, e.g. the police (criminal checks) or training providers (accrediting qualifications).

***Key finding:***

Overall, both life stage and working experience/employment sector clearly influenced understanding of regulation.

## **5.2 Understanding of which professions are regulated (spontaneous)**

**The starting point for this discussion was typically one respondent asserting their hope that all health and care professions would be in some way ‘supervised’.** On closer examination of the list of health professionals (stimulus A):

- **All assumed that traditional clinical professionals, i.e. surgeons, doctors and nurses working within either an NHS or private setting, would be regulated.** Participants’ confidence in this view was based on an assumption that anyone making potentially ‘life or death’ decisions would necessarily be regulated.
- **Most also made an assumption that those practising complementary therapies were the least likely to be regulated,** largely because these were not perceived to be ‘clinical’ professions in the traditional sense of the word.
  - When considering whether there was a risk of harm for users of complementary therapies, participants tended to focus on more obvious physical risks e.g. misuse of acupuncture needles.

- **A judgement about whether other practitioners (e.g. allied health professionals) were regulated was felt to be determined by the environment in which they practised:**
  - Participants felt that a practitioner providing treatment in a hospital setting (e.g. dietician, optician, dentist) was more likely to be regulated than their equivalent delivering services in an independent setting;
  - Practitioners more likely to practise in-home (e.g. counsellors and complementary therapy practitioners) were not expected to be regulated.
  
- **Participants had a higher expectation of regulation within a hospital setting compared to independent practitioners and in-home settings for two key reasons:**
  - Firstly, the NHS brand conferred reassurance regarding safety;
  - Secondly, there was a belief that working amongst other statutorily regulated health professionals in either NHS or private hospital settings would involve sharing protocols for safety and quality, as well as being exposed to potential whistle-blowing by other staff.
  
- **Those with more knowledge of home care services or residential care homes (either as carers or who knew care workers personally) were aware that care workers were not qualified.** However, this small group of participants were equally aware that home care services and residential care homes were regulated. For example, one respondent had heard of the CQC, and others could cite examples of regulatory activity e.g. Deprivation of Liberty Safeguards, EU directives.

***Key finding:***

Participants made assumptions about which professions were regulated and which were not based on: the potential to cause harm (perceived to be highest amongst traditional clinical practitioners and lowest amongst complementary practitioners) and the setting in which practitioners were practising. They made an assumption that hospital and care home

settings were regulated, and that independent and in-home settings were less likely to be regulated.

### 5.3 Perceptions of potential harm (spontaneous)

Right-touch regulation sets out that regulation should only be used where patients or service users may in some way be harmed by the behaviour or actions of the people delivering care. So, we sought to understand the perception – both spontaneous and on reflection – of patients and service users on different types of harm.

**Perceptions of harm were immediately and spontaneously linked to examples of physical harm** as a result of (for example): inaccurate diagnosis, poor advice, dispensing the wrong drugs or stipulating the wrong dosage, or overlooking something important:

- **Initially, the examples of harm tended to be associated with the NHS system as a whole, rather than with individuals delivering care.** The most common discussion focused on harm (both mental and physical) being caused by long waiting times and a perceived lack of resources: *“They are operating on the bare minimum.”* Poor communication between services was also cited as a potential cause of harm. One respondent (31-55 years old) reported that poor communication between NHS hospital departments had led to someone she knew having an exploratory operation, during which the patient died. Another (also 31-55 years old) reported that her recent experience of maternity services had revealed poor communication between different NHS organisations. Once again she felt that poor communication had the potential to cause harm.
- **Although many felt that the risk of harm was greater in an NHS hospital, those with experience of private hospital services did not necessarily agree:**
  - One respondent reported that his mother had an operation in a private hospital and lost a lot of blood because no one responded to her call button;
  - Another respondent described how his private hospital room was in a remote part of a converted house where he felt isolated from help.

- **Generally, participants were less willing to entertain the idea of purposeful or cynical harm being caused by any health or care practitioner** - with the exception of social care workers.
  - Examples of harm within the home care setting have been well publicised by the media. Participants in each group described stories of older care service users being mistreated physically (e.g. neglect and physical abuse) and mentally (e.g. bullying): *“It’s rife at the moment.”* They also discussed the risk of theft.

Participants clearly found it easier to entertain the idea of harm resulting from overall care or service inadequacies. They were more reticent to blame individual practitioners.

**After some discussion, two levels of harm emerged:**

- **Catastrophic harm** – death, injury, long-term illness. For example, it was suggested that a paramedic might need to make decisions about how to preserve life, possibly at the risk of other injuries.
- **Adverse effect on quality of life.** For example, it was suggested that a hearing aid dispenser not adjusting a hearing aid adequately could result in a service user not being able to hear as well as they might.

**A few reported their own experience of harm – of both types - that they perceived had been caused by a health professional:**

- One female respondent (31-55 years old) felt that a physiotherapist had given her the wrong exercises for her knee which had an adverse effect on her recovery from a knee operation;
- A male respondent (31-55 years old) reported that his partner had been mis-diagnosed and unfortunately, when accurately diagnosed, found that he had very little time to live;

- A male respondent (56-75 years old) described how his daughter had been frightened by a GP and was now very reticent to go to the GP surgery at all – despite an apology letter from the individual GP concerned.

***Key finding:***

Perceptions of harm were immediately and spontaneously linked to examples of physical harm. Participants clearly found it easier to entertain the idea of harm resulting from overall care or service inadequacies. They were more reticent to blame individual practitioners.

#### **5.4 Perceptions of harm associated with specific settings**

Participants were prompted to consider the types of harm that could be associated with different settings (stimulus B).

- **Homecare was a setting where service users were felt to be particularly vulnerable to a range of different types of harm.** Participants identified two factors which they felt contributed to home care service users' perceived vulnerability:
  - Home care workers not having specific qualifications, being poorly paid and being required to complete tasks within unrealistic timescales;
  - Elderly patients receiving care being potentially less likely to recall harm, as well as being generally less able or willing to report cases of harm.
- **Those with direct or indirect experience of mental healthcare felt that this was a high risk setting where the potential for harm would be difficult to assess:** *"It only takes one person on one occasion to say the wrong thing ..."* In this setting, participants felt that the potential consequences of harm could involve individuals further harming themselves, or others around them. Those in the 18-30 and 31-55 year old groups identified mental health service users as particularly vulnerable to potential harm, due to the use of unobserved, one-to-one settings for various types of therapy, which they felt could make service users vulnerable to manipulation and 'abuses of power'.

- **Complementary care was identified as an area where participants felt that harm could result from inexperience, or insufficient attention to quality assurance protocols** (which participants assumed would be required to deliver consistently high quality care).

Once again, suggested examples of harm focussed on physical harm e.g.:

- Aromatherapists using oils to which someone is allergic;
- Acupuncturists misusing needles;
- Contents of Chinese herbal remedies: *“You don’t know what you’re ingesting.”*

- **The type of harm associated with private practitioners working from private consulting rooms was perceived to depend on the individual’s speciality.** For example, physical harm was felt to be a potential risk for those using private physiotherapists. However, there was an awareness that many private practitioners also work within the NHS.

These private practitioners were felt to pose less of a risk. For example, one respondent had consulted a dermatologist with a clinic in a bungalow! Despite the rather non-clinical setting, she felt confident because the consultant also worked within local NHS services<sup>1</sup>.

- **Participants were also asked to consider whether harm could result from decisions made in an entirely non-clinical setting - by NHS Managers.** Participants clearly felt that NHS managers had the potential to cause harm throughout the system, albeit as an indirect consequence of decisions made about services. Some even worried that an NHS manager without clinical experience could make financially driven decisions that could conflict with the assumed interests of clinicians – patient care. This form of harm, although indirect, was felt to be potentially widespread and far-reaching.

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<sup>1</sup> Recent research conducted on behalf of the CQC which aims to define ‘good’ from a user’s perspective found that private patients generally felt more vulnerable when using independent practitioners’ consulting rooms than when being treated in private hospitals. The ‘hotel’ aspects of the private hospital experience were lacking in independent consulting rooms and the sense of confidence patients derived from their environment therefore decreased.

**Key finding:**

When prompted to consider a wider range of settings, participants identified that harm could result from practitioners practising in a range of settings including home care, mental health care, complementary care, independent settings and even non-clinical settings (via decisions made by NHS managers).

**5.5 Perceptions of harm (prompted)**

When prompted with a wider range of examples of harm (stimulus C), the following categories were consistently identified: physical, mental, criminal and unethical. The first two categories focussed on the type of harm caused to the service user (i.e. physical or mental); the second two categories focussed on the behaviour of the health professional (i.e. either criminal or unethical).

The examples of harm which participants felt most passionately about were examples involving physical harm. Since these examples were considered the most serious, participants often made value judgements about the behaviour of the health professional, which was often (but not always) described as ‘criminal’, as described in the table below:

**Note: for full examples please refer to ‘section 2. Perceptions of potential harm’ of the topic guide document in APPENDIX A**

		Type of behaviour	Harm caused
Group 1	Childbirth	Criminal	Direct - physical
	Unnecessary force	Criminal	Direct physical and mental
	Homeopath	Unethical	Direct - physical

Participants were clearly able to identify examples where they felt that the behaviour of the health or care professional had the potential to cause mental distress. In these situations, the behaviour of the health or care professional was more typically described as ‘unethical’ rather than ‘criminal’, as described in the table below:

		Type of behaviour	Harm caused
Group 2	Patient not being given privacy to undress	Unethical	Direct - mental
	Social worker in the pub	Unethical	Direct - mental
	False memory syndrome	Unethical	Direct - mental

Interestingly, there were only two examples where participants felt that harm could be caused simply as the result of poor practice. In these cases, participants did not make value judgements about the health professional's behaviour, they simply felt that their practice needed to be improved, as described in the table below:

		Type of behaviour	Harm caused
Group 3	Nurse breaching confidentiality	Poor practice	Direct – mental
	MRSA	Poor practice	Direct – physical

There were two examples of indirect harm which participants thought would be caused by criminal behaviour. Theft from a patient was clearly felt to affect the individual, but a health professional committing fraud was potentially felt to affect all NHS patients – albeit indirectly.

		Type of behaviour	Harm caused
	Fraud	Criminal	Indirect harm
	Theft	Criminal	Indirect harm

**Interpretation of the example of the social worker working as a call girl was dominated by value judgements made about the health professional's behaviour.** Most participants felt that this behaviour was 'unethical', but none could clearly articulate why this behaviour had the potential to cause harm. One respondent (the only one!) felt that *"what the social worker does in her spare time is nobody else's business"*.

**The example which created most debate in the 56-75 year old group was the homeopath suggesting that homeopathy could contribute to a ‘cure’ for a cancer patient.** A majority felt that this behaviour was clearly unethical, since most were of the opinion that homeopathy could not be viewed as a treatment for cancer, and to suggest so was misleading. They also felt that the patient was vulnerable to being made unrealistic promises and that this could constitute ‘harm’: *“You’re dealing with a lot of vulnerable people who want to hope.”* However, a cancer survivor in the group argued that choice of treatment was a matter of personal choice, and that cancer patients are likely to welcome any treatment that might be helpful. The group agreed that clarity would be important in this situation: the practitioner would need to be clear that homeopathy cannot cure cancer.

**One respondent from the 56-75 year old group claimed that his family GP had used complementary remedies to treat his daughter for childhood illnesses, but they had only found out that he had done so fairly recently.** When they discovered that this had been the case they challenged the GP, who reportedly said that he ‘didn’t think their daughter deserved to have drugs inside her’. The respondent was now in two minds about his experience: while he does not feel that his daughter was disadvantaged by being treated with complementary remedies, he would have liked to have been told about it.

**Overall, most examples were considered to be examples of deliberate harm.** This is likely to be a consequence of the way in which the stimulus was presented: participants were asked to review clearly defined examples, out of context. They were therefore not encouraged to consider the broader circumstances in which these incidents had taken place, or the various complexities any health professional might be contending with at any one time. It was rare for participants to empathise with the complexities that health professionals need to contend with. A rare example was raised by a respondent who knew a care worker responsible for giving people medication. She explained that they had a responsibility to ensure that patients take their medication, recognising that forcing someone to take their medication would constitute assault and that personal choice was a factor that needed to be considered.

**Overall, participants focussed on what they imagined would be the immediate consequences of the health professional's behaviour.** Much less thought was given to the potential for longer term harm. A rare example was a respondent pointing out that the therapist inducing a patient to have false memories could not only cause mental harm, but in the longer term could 'trap' the patient into paying for their services for a very long time.

***Key finding:***

When prompted with a range of examples, participants identified two broad categories of harm ('physical' and 'mental') resulting from two broad categories of behaviour ('criminal' and 'unethical'). Physical harm was more likely to be described as the result of 'criminal' behaviour than mental harm which was more likely to be described as the result of 'unethical' behaviour.

### **5.6 Groups particularly vulnerable to harm**

As described in section 4.3, older people were felt to be particularly vulnerable to potential harm when using residential and home care services: *"You're in bed and they've got a key to your house."* The vulnerability of this group in terms of their ability to protect themselves from harm was clear to all. For example, a carer in the 56-75 year old group explained how his parents were vulnerable to scam mailings.

**Other vulnerable groups included other people unable to protect themselves from harm e.g. young people and people with disabilities.** One respondent described the vulnerability of the children with learning disabilities she worked with: *"Because they don't have their own voice ... those [play] therapists are helping them with those problems. If the therapists are misdiagnosing the problems or missing the problems altogether, those children literally don't have a voice. If things are missed, some really quite terrible things could go on happening."*

**More generally, participants felt that all of us are potentially vulnerable to harm in hospital, when feeling poorly or having invasive treatment.** MRSA was identified as a

particular threat to anyone finding themselves in hospital. More generally, all non-health professionals were felt to be relying on health professionals' knowledge and training when receiving treatment. As non-health professionals, participants felt that they lacked the knowledge to question or challenge decisions. It was also pointed out that it may not necessarily be obvious to patients if a health professional has been negligent in some way. However, in the event of problems arising, some groups were felt to be even less able to assert themselves than most - people with less confidence or life experience.

**One respondent shared her experience of trying to understand how treatment on her knee has not resulted in a positive outcome.** She had sought different opinions about the effect her treatment had had and therefore what type of remedial treatment she needs. However, different health professionals have expressed different opinions and she is now uncertain about how to proceed: *"As a user of these services, we're not going to know. We are in their hands, we're not experts."* The respondent knows that her knee needs remedial treatment, but she remains unsure what remedial treatment to have.

***Key finding:***

Older people using care services, young people and people with disabilities were identified as particularly vulnerable to harm. Equally, when feeling poorly and using health and care services, participants felt that all of us are vulnerable and reliant on the skill and experience of health and care professionals.

### **5.7 Less visible harm**

**Participants were prompted to identify examples of less visible harm.** Less visible harm was consistently recognised as harm that is less likely to be reported, and was often associated with:

- Vulnerable service users e.g. older people who may be unable to speak up for themselves and may be less inclined to complain than younger people, as well as those with learning difficulties, and those with disabilities;

- Longer term effects of harm e.g. mental health consequences, losing a job, relationship problems;
- Psychological harm;
- Intangible forms of harm e.g. embarrassment, or humiliation.

**Participants were able to give examples of their experience of less visible harm.** For example, one respondent felt that the uncertainty of his wife’s current health situation was putting her employment in jeopardy and their relationship under considerable strain. Another respondent reported that his daughter was now unwilling to visit the GP after she felt that he had spoken to her rudely.

**Participants recognised that ‘less visible’ types of harm were difficult for a regulator to identify – and sometimes difficult for patients to evidence.** For example:

- Breaching confidentiality (would need to be witnessed);
- Psychological harm (difficult to evidence and witness) e.g. false memory syndrome: *“You can’t see scars on the brain.”*

Having considered a range of different types of less visible harm, participants realised that **the only way a regulator would become aware that a patient felt that harm had been caused by a health professional would be if someone made a complaint or insurance claim.**

**The only way participants had heard of organisations trying to make harm more visible was the installation of cameras in some care settings.** In fact one carer in the 56-75 year old group had been asked his permission for a camera to be installed. Participants appeared to be comfortable with cameras being installed in settings where service users were clearly vulnerable.

**To make less visible forms of harm more visible, participants suggested that those receiving care need to be prepared to feed back about the care they receive.** The more knowledgeable 31-55 year old group also suggested that health professionals’ notes were

another way in which evidence of less visible harm could be captured. (This group also suggested that asking patients to review notes was a way of preventing potential harm – that is, if patients are able to challenge what has been recorded and if the subsequent interventions are made to prevent any recurrence.)

***Key finding:***

When prompted, participants were able to identify examples of less visible harm and became aware that these types of harm would only become visible if the injured party made a complaint or an insurance claim.

## **5.8 Current patient feedback**

Regulators find it difficult to obtain evidence of risk. One source of evidence is, of course, patients and service users themselves. Therefore, the PSA is interested to explore how patients and service users may feed into the evidence base for developing policy, either by direct or indirect ways.

### **Participants reported offering feedback to services in a number of ways:**

- Comments cards (e.g. private dental services);
- Contacting PALS service when in hospital;
- Complaining (e.g. about wanting to see a consultant, not 'junior' members of staff);
- Visit from a Trust governor while staying on a maternity ward.

**There was felt to be a natural bias towards giving feedback when services had performed either very well or very badly.** Older participants (56-75 years old) also felt that generally, patients had a natural inclination to thank staff verbally, rather than comment on their behaviour in writing.

### **Barriers to giving feedback were also identified:**

- A perception that feedback will not make a difference: *“You think, ‘is it actually worth it?’;”*
- A perception that offering feedback will be time-consuming (a particular barrier for the younger group);
- Service users might potentially feel less comfortable to provide feedback if they are using services for very personal reasons (e.g. sexual health);
- A lack of response: for example, the respondent who had contacted the PALS service by email during a long stay in hospital had only received an acknowledgement email, but not a response which had been extremely disappointing.

**Although participants reported different examples of providing feedback, these examples all involved offering feedback to providers.** A minority pointed out that offering feedback about individual health professionals or feeding back to a regulator was a rather different concept. Individual participants pointed out that there might be limitations to the type of feedback patients were willing to offer about a specific health professional:

- One respondent suggested that patients might feel more vulnerable when commenting on the behaviour of one specific individual: *“If you give them bad feedback, are they going to be horrible to you?” “I might feel vulnerable in case I upset them or their colleagues.”*
- Another respondent acknowledged that some patients were probably more likely to offer feedback about their overall experience and the health professionals in charge of that experience (e.g. consultant), rather than individual parts of that experience (e.g. radiographer): *“You would want to comment on the person that makes the pie, not the one who puts in the pie filling.”*
- One respondent (who had experience of cancer treatment) felt that she would be unable to comment on whether individual health professionals had done a good job.

**Participants were less interested in the concept of engaging with the regulator because:**

- The method by which they might feedback to the regulator was less established (than feeding back directly to services);
- Outcomes of their efforts to feedback information would likely be unknown;
- The PSA (and most other regulators) were not very well known – with little (or no) brand association;
- There was a perceived time commitment (i.e. potentially more time than directly reporting back on services with the provider).

***Key finding:***

Although participants reported different examples of providing feedback, on these occasions they had been motivated to offer feedback based on the need to improve care.

**5.9 Encouraging patients to offer feedback**

**Currently, participants did not feel that patients were encouraged to offer feedback.**

Firstly, they did not feel that they knew *how* to offer feedback: *“It’s knowing who to go to, that’s a lot of the problem.”* Secondly, feedback channels were not felt to be sufficiently fast, clear or convenient; and there was a belief that they would need to be so in order to encourage people to use them. Relying on service users to offer feedback proactively was considered “unrealistic”. Ultimately, participants felt that the feedback process needed to be a more integral part of the process of receiving care.

**The type of feedback that would be useful was also debated.** Participants were seeking a style of feedback that would be helpful to the organisation, but also encourage patients to believe that their feedback was valued. For example, some felt that patient questionnaires were rather generic and formulaic and others preferred more qualitative methods e.g. ‘back to the floor’ exercises and patient panels.

***iwantgreatcare.org* was felt to be a progressive idea with positive intentions;** however, many felt that it was ‘too subjective’ and open to manipulation (much like TripAdvisor,

checkatrade or trustatrade): *“What stops someone ruining someone else’s career?” “Them that are proactive [i.e. in getting patients to rate them] will rise to the top.” “How do we know that people have really been treated by this person.”* Participants felt that it was important to systematically collect information from patients, rather than relying on people to ‘opt in’ to providing feedback on this type of site.

The ***Friends and Family Test*** was viewed more positively as something that could be integrated into the patient experience (e.g. quickly filling in a comments card whilst waiting to be discharged). The swift ‘tick box’ exercise was appreciated for its brevity, but younger participants (18-30 years old) still appeared to be less motivated than others to complete the short survey.

**In order to feel more motivated to offer feedback, participants felt that:**

- **Ways of providing feedback would need to be more easily identifiable and accessible;**
  - Younger people in particular wanted to be able to give feedback quickly – a ‘tick box’ approach appealed to this group who were not prepared to invest much time on feedback;
  - Participants suggested that different levels of feedback could be offered e.g. a concise questionnaire, with the option to add more detail, if wished.
  
- **Organisations need to be more prepared to listen to feedback.** A number of participants claimed that they had made complaints or given feedback in the past, but had either not been satisfied with the response, or not convinced that their information had been heard: *“It’s unclear what decisions will be made as a result of my feedback and whether they will be the right decisions or not.”* For example, one respondent had complained about his GP, only to be told that he was able to sign on with another GP in the area if he was unsatisfied with his current GP. He was clearly dissatisfied with a process which did not reassure him that the organisation had understood his point-of-view.

- **Organisations need to demonstrate how they have listened to feedback and how much it is valued, for example:**
  - One respondent remarked that supermarkets sometimes publicise their response to customer feedback, *“You said this, so we did that.”*
  - Another pointed out that the results from the questionnaires Ofsted asks parents to complete during their school inspection process are published on their website.
  - Another felt that restaurant-style ‘scores on the doors’ could be a relevant concept in the health setting.

***Key finding:***

To motivate more people to offer feedback, participants suggested that: feedback channels would need to be publicised; feedback mechanisms would need to be fast, clear and convenient; and that organisations would need to demonstrate that they have acted on feedback to improve services.

### **5.10 Options for feeding into the evidence base**

As well as gaining information from patients and service users in general, the PSA also wishes to explore the potential for using expert patients and service users.

**Overall, the idea of a regulator using ‘experts by experience’ was well received** – and was certainly considered a much better idea than a regulatory version of *iwantgreatcare*. However, some of the same limitations were felt to apply. Some were concerned that a range of ‘experts by experience’ would need to be chosen to reflect a cross-section of experience (i.e. so that feedback is not monopolised by people with a particular axe to grind).

**A willingness to provide feedback to a regulator was more noticeable amongst those who were heavily invested in their health condition.** These individuals were more open to the

concept of becoming ‘experts by experience’. Some amongst the older 56-75 year old group had experience of supporting services from a user perspective. One had been asked by a specialist stoma nurse to talk to other patients about stoma care, which she had willingly agreed to do. Another cancer survivor had been asked to attend a nursing conference to speak about her experience of cancer treatment. Once again, she had been more than willing to do so. Another respondent was a member of his local HealthWatch and regularly visits local services to chat to patients about their experiences.

***Key finding:***

The appetite to become an ‘expert by experience’ was driven by ongoing interest in niche conditions (e.g. lifelong skin condition) and supporting services to provide quality care for users with similar conditions. It seems likely that ‘experts by experience’ would be more motivated to support the development of niche areas of regulation e.g. a particular type of nursing rather than nursing in general. They would also need to understand how their involvement would benefit services - and ultimately patients.

### **5.11 Models of oversight of health and care professionals**

The philosophy of Right-touch regulation is that methods of oversight and the level of regulation should protect patients and service users, but not be overly burdensome. This could be achieved by targeting areas of risk.

Models of oversight range from compulsory registration of a health or care professional to a code of conduct for those working in a particular occupation with employers making sure they comply with the code. So, the PSA wished to understand participants’ views of different models.

#### ***5.11.1 Compulsory registration with a body that has the power to set standards for entry to the profession and exclude people from a profession or area of practice***

This level of regulation was considered to be the ‘gold standard’ and ideally, a standard

a majority would wish to achieve for all health and care professionals (even those who are not currently regulated e.g. care workers).

**Clearly, most participants did not understand the implications of instituting this level of regulation for all health professionals.** It was only the 31-55 year old group who pointed out that this is a costly and time-consuming option, particularly since any system of regulation needs to be monitored on an ongoing basis. A majority simply felt that this was the level of regulation which afforded users a sense of certainty in terms of quality standards and visible lines of accountability: *“What price safety and peace-of-mind?”*

When participants had been prompted to consider the cost of implementing this level of regulation for all health professionals, **it was decided that this level of regulation would be most appropriate for clinical staff such as surgeons, doctors, nurses and midwives** largely because patients’ lives are at stake.

#### ***5.11.2 A government-sanctioned barring scheme – individuals do not have to be registered to practise but if they commit serious misconduct, they can be excluded from an occupation***

This was felt to offer a degree of certainty for services users, particularly in terms of safety, since those considered unsafe to practise would face consequences i.e. being ‘struck off’. However, beyond basic safety, participants could see that this system would not provide any reassurance regarding quality because individuals do not have to be registered to practise. In this sense, this system was felt to regulate very bad practice, but did not offer any other type of regulation of ‘non-bad’ practice i.e. standards of practice.

#### ***5.11.3 Voluntary registration with a professional body that conforms to standards set by Government***

The voluntary basis for this proposition was not felt to provide regulation for a whole profession, but only the health professionals within the profession wanting to be regulated.

A code of conduct for those willing to be regulated was well received, but the lack of consequences (i.e. the option to 'strike off' the register) was not considered sufficient.

Participants understood that this option would allow practitioners to differentiate themselves and provide patients with a way of making a positive consumer choice, particularly if supported by a kite mark. They could also appreciate that this option would provide a cheaper alternative to the 'gold standard' system of regulation they preferred.

For the practitioners who were not considered to hold patients' lives at stake (i.e. those other than surgeons, doctors, nurses and midwives), voluntary membership to an accredited register and associated kite mark was felt to be sufficient – provided:

- The feedback process is easily identifiable, seamless and confidential;
- There are ongoing processes in place to ensure that professionals are still fit for practice;
- Professionals can be 'struck off' as a result of feedback that is deemed high-risk by the regulator.

It was suggested that employers or individuals could finance these additional elements (which would effectively create a system that satisfied participants' desire for a 'gold standard' approach for all).

The kite mark was a strong element of this proposition, since participants felt they would become habituated to recognising the kite mark and more likely to make informed decisions about which professionals would be more committed to quality, and therefore less likely to cause harm. (Those who had chosen private practitioners explained that they had researched their options, using online information.) Overall, participants felt that they would trust a kite mark, which would symbolise that there was someone monitoring standards and would introduce sanctions for misconduct, if necessary.

#### ***5.11.4 Voluntary registration with a professional body***

The voluntary basis for this proposition was not felt to provide regulation for a whole profession, but only the health professionals within the profession wanting to be regulated. For those wanting to be regulated, the support of a professional body was considered advantageous, but there was assumed to be a membership cost which participants felt might be off-putting.

Overall, participants did not feel that this system was sufficiently stringent given that:

- It is voluntary, and is therefore only likely to attract those actively wanting to be regulated;
- Lacks standards to which even those who wish to be regulated are required to conform;
- And also lacks any sanctions for those committing misconduct.

#### **5.11.5 A code of conduct for people working in a particular occupation with employers making sure that people comply with the code – no powers to exclude from the occupation**

Participants perceived this as a very weak option (although they recognised that it would be cheap to implement). They complained that a 'code of conduct' did not reassure them that practice would be monitored, particularly since employers would not have any powers to exclude from the profession. They did not feel that practitioners would be properly held to account and perceived this approach as more of an 'aspiration for good governance'.

#### ***Key finding:***

Overall, participants wanted a regulatory approach which included the following elements: ongoing processes to ensure that professionals are maintaining fitness to practise standards and sanctions for those who are proved to be unfit to practise. A voluntary register was considered appropriate for the practitioners who were not considered to hold patients' lives at stake, as long as it was supported by a kite mark system.

## 5.12 Information requirements

**At the end of the discussion, when the complexities of regulation had become apparent, the demand for information was consistent.** Participants expressed an appetite to understand:

- Which professionals are subject to statutory regulation and which professionals are not?
- and of those who are not, which professionals are on the accredited register and which professionals are not?

**Participants also desired a single source of information about regulation,** since they had become aware that they did not know where to go to find this information and that many, many organisations were involved. A 'one stop shop' was envisaged that would be accessible to all and not only available online. Publicising this 'one stop shop' was considered important *"so we have better knowledge of who to go to, like Ofgem and Oftel"*. Participants suggested promoting the 'one stop shop' within health and care services (e.g. GPs, dentists and hospitals (for example, hospital TV)); in the community (for example, libraries and local papers); and online.

***Key finding:***

Alerting participants to the complexities of regulation created an appetite to know more about it. In future, a single source of information explaining the regulatory structures for different professions would be appreciated.

## 6. Findings and policy implications

### *Perceptions of professional regulation*

From the three workshops, it was clear that both life stage and working experience/employment sector clearly influenced understanding of regulation. Participants made assumptions about which professions were regulated and which were not based on: the potential to cause harm (perceived to be highest amongst traditional clinical practitioners and lowest amongst complementary practitioners) and the setting in which practitioners were practising. They made an assumption that hospital and care home settings were regulated, and that independent and in-home settings were less likely to be regulated.

- ➔ More information could be made available to patients and service users about the levels of assurance that are in place for different professional groups. A single source of information explaining the regulatory structures for different professions would be helpful.

### *Perceptions of harm*

Perceptions of harm were immediately and spontaneously linked to examples of physical harm. Participants clearly found it easier to entertain the idea of harm resulting from overall care or service inadequacies. They were more reticent to blame individual practitioners.

When prompted to consider a wider range of settings, participants identified that harm could result from practitioners practising in a range of settings including home care, mental health care, complementary care, independent settings and even non-clinical settings (via decisions made by NHS managers).

When prompted with a range of examples, participants identified two broad categories of harm ('physical' and 'mental') resulting from two broad categories of behaviour ('criminal' and 'unethical'). Physical harm was more likely to be described as the result of 'criminal' behaviour than mental harm which was more likely to be described as the result of 'unethical' behaviour.

Older people using care services, young people and people with disabilities were identified as particularly vulnerable to harm. Equally, when feeling poorly and using health and care services, participants felt that all of us are vulnerable and reliant on the skill and experience of health and care professionals.

When prompted, participants were able to identify examples of less visible harm and became aware that these types of harm would only become visible more widely if the injured party made a complaint or an insurance claim.

- ➔ Governments and regulators should consider the wide range of settings in which health and social care are provided when seeking evidence of harm to patients and service users.
- ➔ Any definition of harm needs to encompass mental as well as physical health, direct and indirect harm <sup>2</sup>and visible and less visible forms of harm.
- ➔ Policy-makers should also consider the greater vulnerability to harm of certain groups of service users or of people in a vulnerable state.
- ➔ Policy-makers should be aware that some types of harm are less visible than others.

#### ***Views on feeding into the evidence base for regulatory policy***

Although participants reported different examples of providing feedback, on these occasions they had been motivated to offer feedback based on the need to improve care.

To motivate more people to offer feedback, participants suggested that: feedback channels would need to be publicised; feedback mechanisms would need to be fast, clear and convenient; and that organisations would need to demonstrate that they have acted on feedback to improve services.

The appetite to become an 'expert by experience' was driven by ongoing interest in niche conditions (e.g. lifelong skin condition) and supporting services to provide quality care for users with similar conditions. It seems likely that 'experts by experience' would be more motivated to support the development of niche areas of regulation e.g. a particular type of

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<sup>2</sup> Direct harm is to the patient or service user's health, indirect harm is through, for example, the negative impact on NHS funding, policies or confidence in a profession or occupation

nursing rather than nursing in general. They would also need to understand how their involvement would benefit services - and ultimately patients.

- ➔ Governments and regulators need to think creatively about how to engage members of the public in gathering evidence of risk to patients and service users, where possible make use of existing local feedback channels, and explain how involvement will benefit patients.

### ***Views on different models of assurance***

Overall, participants wanted a regulatory approach which included the following elements: ongoing processes to ensure that professionals are maintaining fitness to practise standards and sanctions for those who are proved to be unfit to practise. A voluntary register was considered appropriate for the practitioners who were not considered to hold patients' lives at stake, as long as it was supported by a kite mark system. Alerting participants to the complexities of regulation created an appetite to know more about it.

- ➔ Considerable awareness raising activity will be required for any kite-mark scheme that is designed to help service users make informed choices.

## APPENDIX A – TOPIC GUIDE

### PSA Right-Touch Regulation

	ACTIVITY	Time
	<b>1. Introduction</b>	<b>10 mins</b>
	<p><b>Welcome</b></p> <p><b>Awareness of PSA</b></p> <p><b>Introduce RWL – independent research agency</b></p> <p><b>Purpose of research – <i>public engagement to gain a closer perspective of how users think decisions should be made on certain elements of regulation.</i></b></p> <p><b>MRS guidelines</b></p> <p><b>Consent to record, transcripts, anonymity</b></p> <p><b>120 mins</b></p> <p><b>Housekeeping</b></p> <p><b>Researcher to read out statement from PSA:</b></p> <p><i>“The organisation we’re carrying out this research for oversee a broad range of health and care professional regulators, from medics, through social workers to complementary therapists.</i></p> <p><i>They believe their methods of oversight and the level of regulation should protect patients and users of these services but not be overly burdensome. This could be achieved by targeting areas of risk.</i></p> <p><i>All governments seem to struggle to find the right balance between over-regulating and under-regulating. This struggle is often cyclical, or like a swinging pendulum – a crisis leads to a decision to introduce more or stronger types of regulation, sometimes without properly considering whether it is the best solution. Sooner or later, there is a backlash – people and businesses feel over-burdened by the demands of regulation, and government moves to a lighter-touch approach. Another crisis occurs, and we swing back again the other way...</i></p> <p><i>The PSA tries to help the people making decisions about who / what to regulate and how, so that they can find the right balance and don’t make these sorts of mistakes.</i></p> <p><i>They would like to understand your views on areas of risk in these services as part of their review of this approach”.</i></p> <p><b>WARM UP</b></p> <ul style="list-style-type: none"> <li>• Introduce selves, age, life status, use of health/social care services, use of therapists outside of the NHS</li> </ul>	<p>Present range of professions that are statutorily regulated, covered by the AR programme</p>

	<b>Opening exercise - researcher to present range of professions and occupations</b> <ul style="list-style-type: none"> <li>• Which of these do you think are regulated any why?</li> </ul>	(or neither)
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	<b>2. Perceptions of potential harm</b>	<b>35 mins</b>
	<p><b>Researcher to read out statement from PSA:</b></p> <p><i>Although it is unusual, health and social care workers can cause harm to the people they are meant to be looking after. We believe that decisions about who is regulated or overseen, and how this oversight should work, should be based on the potential for harm to come to patients and service users. A general note on language: avoid too much discussion about service / environment and try to keep participants more focussed on <u>the professional</u> and government.</i></p> <ul style="list-style-type: none"> <li>○ Based on your experiences of using health and/or social care services, or of seeing therapists outside the NHS, what sorts of harm do you think governments should think about when they are making decisions about regulation? <ul style="list-style-type: none"> <li>○ What sorts of harm do you think regulators should think about when they are making decisions about regulation?</li> </ul> </li> <li>○ What is the potential for harm in different healthcare settings? <p><i>Spontaneous and then probe for each setting:</i></p> <ul style="list-style-type: none"> <li>○ NHS hospital</li> <li>○ Private hospital</li> <li>○ Private practitioner’s consultation rooms</li> </ul> </li> <li>○ What is the potential for harm with different types of care that might involve the range of practitioners involved? <i>Spontaneous and then probe for each setting:</i> <ul style="list-style-type: none"> <li>○ Physical care or mental health care</li> <li>○ Complementary therapies</li> <li>○ Doctors / nurses / dentists</li> <li>○ Nurses</li> <li>○ Dentists</li> <li>○ NHS managers</li> <li>○ Home care workers</li> <li>○ Homeopaths</li> </ul> </li> </ul> <p><b>Explain:</b> which are regulated statutory on accredited register</p> <p>Can you think of any specific examples of harm that might occur across any of these settings? Spontaneous and then probe examples – do they all represent harm?</p> <ul style="list-style-type: none"> <li>○ a patient developing a hospital-based infection because of a nurse</li> </ul>	<p>Hand out example sort cards – including blank cards for participants to add their own ideas</p>

	<p>maintaining poor hygiene standards in an NHS hospital</p> <ul style="list-style-type: none"> <li>○ a baby being harmed in childbirth because of poor communication between the midwife and the obstetrician</li> <li>○ a psychotherapist inducing ‘false memory syndrome’, where the therapy induces false memories about a traumatic event in the patient’s distant past, perhaps suggesting that they were mistreated by a family member or friend</li> <li>○ a patient not being given the option to undress privately in a physiotherapy consultation</li> <li>○ a mental health nurse using unnecessary physical force to restrain a patient</li> <li>○ a cancer patient being persuaded by a homeopath that complementary therapies can help cure cancer</li> <li>○ a social worker socialising in the pub with a young service user who has a history of alcohol abuse</li> <li>○ a social worker working as a call-girl in her spare time</li> <li>○ a home care worker stealing small sums of cash from an elderly patient</li> <li>○ a dentist fraudulently requesting payments from the government by forging the signatures of NHS patients and falsely claiming that they have treated them</li> <li>○ a nurse breaches patient confidentiality by talking very loudly in front of other patients</li> </ul> <p>○ Thinking about these examples of harm, are you able to consider ways in which they could be categorised?</p> <p><b>Researcher:</b> <i>spread example sort cards out on the table and ask respondent to organise them into specific categories. Allow participants 5 minutes to complete this sorting exercise.</i></p> <ul style="list-style-type: none"> <li>○ Looking at the groupings [ensure that where prompts fall into more than one category – ensure this is recorded using the code]: <ul style="list-style-type: none"> <li>▪ Do they relate to the competence or behaviour of the worker?</li> <li>▪ Are they deliberate or inadvertent?</li> <li>▪ Do they affect people physically or emotionally?</li> <li>▪ Do they affect individuals directly or indirectly?</li> <li>▪ Are they criminal offences?</li> <li>▪ Are some people more vulnerable to this type of harm than others? If so who?</li> </ul> </li> <li>○ Explore <u>consequences</u> of harm across the established categories.</li> <li>○ What might be the consequences of harm across the categories?</li> </ul>	
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	3. Visibility of harm	15 mins
	<p><b>Researcher explain:</b> <i>now that we have discussed different forms of potential harm across a range of different settings, we would now like you to think about which of these types of harm are more or less visible from the perspective of the those regulating services.</i></p> <ul style="list-style-type: none"> <li>• Do you think there are types of harm that are <u>less visible</u> to the people making decisions about regulation? Why? <ul style="list-style-type: none"> <li>○ What could be done to make them <u>more visible</u>?</li> <li>○ How do you think <u>you</u> could contribute to the evidence that is used to influence decisions about regulation and oversight?</li> <li>○ How might others, outside of the group, contribute?</li> </ul> </li> <li>• Participants to organise examples of harm cards again into two separate groups i.e. ‘more visible’ and ‘less visible’ to regulators:</li> <li>• <b>Moderator:</b> also introduce <u>blank cards</u> for participants to add their own examples of harm that might be more/less visible to regulators</li> <li>• Probe further ‘less visible’ examples of harm <u>if needed</u>: <ul style="list-style-type: none"> <li>○ Verbal abuse, or bullying of elderly patients with dementia (who may not be able to recall and in turn report this abuse)</li> <li>○ An elderly service user is verbally abused when receiving care in their own home. When receiving physiotherapy for an injury, a client is given exercises to do at home – because of poor advice around this, the client actually injures themselves further, harming their recovery.</li> <li>○ Stopping feeding or bathing leading to mental trauma of patient</li> <li>○ Failing to ensure that a vulnerable service user doesn’t accidentally share personal / confidential information about themselves</li> <li>○ Failing to assist patients adequately with how to take medication and in what quantity</li> <li>○ A patient visits the doctors, but finds them to be rude and unpleasant to deal with – they find this very off-putting and deters them from visiting the doctor again - this stops the patient from seeking treatment for their problem.</li> <li>○ Failing to inform a potential dental patient or service user of the costs involved in their treatment – they may have misconception of the costs involved which could deter them from seeking this treatment</li> <li>○ A person faces social stigma after a mental health professional misdiagnoses them with a mental illness</li> <li>○ A counsellor recommends a particular exercise or treatment for a patient/ client without proper consideration of their stage in recovery/treatment – they may feel unready and could find the process upsetting</li> <li>○ Failing to monitor whether vulnerable patients are actually taking their</li> </ul> </li> </ul>	

	<p>medication</p> <ul style="list-style-type: none"> <li>○ Conflicting ideas around treatment – being advised to stop taking medicine by a complementary health practitioner</li> </ul>	
	<b>4. Options for feeding into the evidence base</b>	<b>20 mins</b>
	<p><b>Researcher explain:</b> <i>now we would like to consider what involvement (if any) you and other patients, service users and members of the public might have in decision making around regulation. <b>Important:</b> ensure that participants are aware that we are interested less formal complaints procedures such as constructive feedback that might contribute to the evidence base for regulation.</i></p> <p><b>For reference:</b> <u>after spontaneous responses are allowed</u>, participants need to be clear on how feedback can be used as supporting evidence for policy development i.e. the difference between positive feedback (i.e. constructive) and negative feedback (complaints) feeds into policy development which can influence which registers should be statutory or not. It also influences how professionals can be assessed in terms of whether or not they are fit for practice on an ongoing basis.</p> <ul style="list-style-type: none"> <li>● Have you ever considered giving feedback on health or care professionals? If yes, how? If no, how might you like to do this?</li> <li>● What would motivate you to give such feedback?</li> <li>● What might prevent you from giving feedback?</li> <li>● [If not already covered in above questions], How might you be involved, on an ongoing basis, in giving feedback or contributing to decisions being made about professional regulation?</li> <li>● Directly to the regulator – would you want to be involved in research by the regulator? Spontaneous and then probe options <u>only if needed</u>: <ul style="list-style-type: none"> <li>○ Would it be better if existing channels were used e.g. the friends and family test; iWantGreatCare.com?</li> <li>○ Would you take part in ongoing work by the regulator e.g. becoming an expert by experience?</li> </ul> </li> </ul> <p>Expert by experience if required: “Experts by experience are people who have experience of using care services. They have first-hand experience of receiving care so they could contribute to ‘expert panels’, which would be taken into consideration for decision making with regards to regulation.</p>	

	<b>5. Government response</b>	<b>20 mins</b>
	<p>Researcher explain: keeping all forms of harm that we have discussed in mind, how visible they are and how involved you/others would like to be with regulation we now</p>	

	<p>want you to think about</p> <ul style="list-style-type: none"> <li>• How do you think Governments can respond to the different risks that are associated with a particular group of practitioners?</li> <li>• What do you think are the advantages and drawbacks of different options presented below:</li> </ul> <p><b>(Researcher to remind participants</b> that options other than regulation may be possible or in place to handle matters of safety, such as the police, Health and Safety regulations and employers dealing with matters within existing systems like appraisal, training, disciplinary measures)</p> <p><b>Moderator:</b> split the group into two teams - <i>allow five minutes</i> for each team to fill out advantages and disadvantages of the TABLE stimulus ‘<b>options for oversight of regulation</b>’. Once completed, participants must present back their table to the other team. Help and encourage participants through this exercise, if needed.</p> <p><b>Options for oversight from ‘light’ to ‘heavy’ touch</b></p> <p>6 A code of conduct for people working in a particular occupation with employers making sure that people comply with the code – no powers to exclude from the occupation</p> <p>7 Voluntary registration with a professional body</p> <p>8 Voluntary registration with a professional body that conforms to standards set by Government</p> <p>9 A government-sanctioned barring scheme – individuals do not have to be registered to practise but if they commit serious misconduct, they can be excluded from an occupation</p> <p>10 Compulsory registration with a body that has the power to set standards for entry to the profession and exclude people from a profession or area of practice</p> <p>➔ <b>Introduce concept of informed consumer and what a kite mark would mean to them.</b></p>	<p>Split into two teams and introduce TABLE stimulus</p>
	<p><b>6. Public information requirements</b></p>	<p><b>10 mins</b></p>
	<ul style="list-style-type: none"> <li>• What do you think the public should be told about professional regulation and complementaries to regulation in health and social care? <i>Probe: accredited register, statutory regulation</i></li> <li>• What do you think Government, regulators and the Professional Standards Authority can do to inform people better?</li> <li>• Where would you like to go to have access to this information? <i>Probe: website</i></li> </ul>	
	<p><b>6. Wrap up</b></p>	<p><b>10 mins</b></p>

*Researcher: using the discussion and the themes participants identified as being more important to health/social care service regulation*

- Return to the most important areas covered
  - Have these changed – anything to add to them that didn't come up before
  
- Views on public involvement in decision-making: how do you feel about this overall having discussed it
  - Final thoughts - any other comments

**THANK AND CLOSE**