# Valuing Individuals: Transforming Participation in Chronic Kidney Disease

## Clinician Support for Patient Activation Measure (CS-PAM) Survey, Cohort 1

**Authors**

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## Introduction

The NHS Five Year Forward View [1] acknowledges the need to support people to manage their health and care.

The Wanless report [2] recommends that unless radical reform takes place within the NHS with patients enabled to take more responsibility for their care, costs will be unsustainable.

The key aim of the Transforming Participation in Chronic Kidney Disease (CKD) programme (TP-CKD) is to empower patients to create partnerships which support them to take greater control of their health and wellbeing, leading to better outcomes for the individual.

So, an empowered or 'activated patient' is one who has been supported sufficiently to develop the knowledge, skills and confidence to make informed and healthy choices about their health and care which are right for them, and who then uses services appropriately to support these choices.

Furthermore, by gaining knowledge, skills and confidence the patient is more able to take responsibility for decisions about their healthcare in partnership with the health care team and so become increasingly independent whilst improving their overall wellbeing.

It would seem obvious that clinical teams also have a key role to play in patient activation or empowering patients, however evidence indicates that they are variable in their levels of support for this way of working [3, 4].

Armed with this knowledge the TP-CKD programme wanted to gain an understanding of how supportive clinical teams involved in the programme were of patients developing knowledge, skills and confidence to become partners in managing their own health before embarking on measuring patient activation. It was decided to measure this support using a tool known as the Clinician Support for Patient Activation Measure (CS-PAM).

The aim of developing CS-PAM was to determine the degree of importance that clinicians attach to specific patient behaviours or skills [3]. Hibbard and colleagues developed the CS-PAM survey by adapting the patient activation measure (PAM), which has been shown to be a valid and highly reliable instrument to measure patient activation [3, 5, 6]. CS-PAM was tested in a primary care setting in staff from the US and UK. Fourteen questions were validated in the CS-PAM development study; 11 of these were directly taken from the PAM and 3 other questions were adapted from behaviours known to correlate with PAM and were relevant to clinical practice [3, 5, 6]. The CS-PAM development study showed that CS-PAM reliably measures the clinician's overall level of endorsement or attitude towards the role of the patient in managing their own health and wellbeing [3]. NHS England further developed the 14 question CS-PAM survey in primary and secondary care and tested and validated 10 extra questions that assess clinical behaviours [4].

In addition to this report, results of the CS-PAM survey are available at centre level and to individual participants. The latter will be available confidentially with a recommendation that it will be used as a reflective tool.

## Methods

Rasch analysis, commonly used in the assessment of abilities or attitudes [4], was used to determine an interval-level, uni-dimensional Guttman-like scale for CS-PAM [3, 6]. The more recent CS-PAM survey, as extended by NHS England [4], was used in this report (see Appendix 1) and measures self-reported behaviours and practices in staff working with CKD patients.

Ten of the 52 adult renal centres in England were invited to participate in the completion of CS-PAM as part of cohort 1. All staff within each centre was invited to participate and the electronic link to access the survey made available to them through the lead clinician. A paper copy of the survey was provided to staff if requested, but the majority of surveys were completed and returned electronically to the UK Renal Registry (UKRR). Where paper copies of the survey were used, surveys returned to the UKRR were scanned into the database. This data was sent to Insignia Health who analysed and returned it as individual CS-PAM scores.

The survey tool consisted of 7 sections and some respondent demographic questions. Questions in sections 1 to 4 focus on the importance to the clinician that their patients with long term conditions follow medical advice, can make independent judgements and take independent action, can function as part of a team caring for their health and are independent information seekers. Choice of answers for these sections was ‘extremely important’, ‘important’, ‘somewhat important’, ‘not important’ and ‘not applicable’. Section 5 relates to the current practice of staff when working with people with long term conditions and tries to determine if staff alter their approach and care according to the knowledge, skill and goals of the patient. The view of staff on the patient’s need and support for information are the focus of section 6. Questions on practice in the last 6 months when treating patients can be found in section 7. The choice of answers for section 5 to 7 is ‘always’, ‘mostly’, ‘sometimes’, ‘never’ and ‘not applicable’ (see Appendix 1 for the CS-PAM survey). Free text fields were provided for each of the 7 sections and free text comments manually ordered in broad categories and included in this report to better understand the views, practices and support needs of staff.

The CS-PAM score is on a 100 point scale. Staff that had an activation score of 100 were excluded from the analysis. Although some variability is expected in the Rasch assessment, it is unlikely that staff are perfectly activated and typically these survey results are excluded from the analysis. Some surveys had many incomplete questions and when not enough questions were answered to allow for a reliable survey and quality standards to be met, these surveys were also excluded.

Three activation levels were calculated by grouping the range of activation scores into thirds to determine the activation levels low, moderate and high. Staff in lower activation levels show lower rates of patient centred behaviours. The Kruskal-Wallis test was used to test for evidence of significant differences in the activation score between groups.

Results were not shown for renal centres when the number of respondents in some categories was too small as this could result in the identification of staff. Too few respondents at centre level also limit the generalisability of results and renal centres with <10 respondents were not shown in the centre level analysis.

Some demographic information was collected on staff: the renal centre they were associated with, gender, age group, ethnic group, if they regularly worked with patients with long term conditions, staff type, setting and speciality/area of work.

## Results from the clinician support for patient activation survey

**Demographic characteristics of staff that completed the survey**

Ten renal centres submitted data as part of cohort 1, with 358 staff members completing the survey. Surveys of staff with an activation score of 100 was excluded (n=41) and some surveys were excluded due to severe incompleteness (n=30), leaving 287 surveys included in the analysis in this report.

The majority of surveys measuring clinical support for patient activation were completed by nursing staff (51.6%), 17.4% by doctors and 15.7% by Allied Health Professionals (AHP) (table 1). The majority of doctors completing the survey were consultants (72.0%), with some trainee and speciality clinicians. The ‘other’ staff category comprised of administrative and clerical staff, health care assistants, technicians, social workers, support workers, care co-ordinators and other non-clinical staff.

The majority of staff were in age groups 34-44 and 45-55 years (33.4% and 30.7% respectively). Staff had many years of work experience with 24.4% having between 21-30 years of experience and 9.1% with ≤ 5 years’ experience.

Female members of staff comprised 69.7% of staff who completed the survey.

The ethnic breakdown of staff that completed the survey is illustrated in table 1: 63.4% of staff were white, with 17.1% and 3.1% Asian and Black staff members respectively.

The majority (88.9%) of staff reported that they regularly work with patients with long term conditions and 1.7% indicated that they do not. Most staff work within an acute hospital setting (69.3%) with 12.5% working outside a hospital setting.

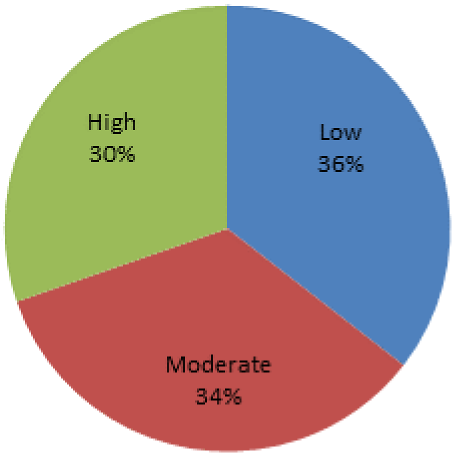
## Table 1 Demographic characteristics for staff that completed the CS-PAM survey

| Staff | Number | Percentage |
|---|---|---|
| Number of staff | 287 | |
| **Staff type** | | |
| Doctor | 50 | 17.4 |
| Nurse | 148 | 51.6 |
| AHP | 45 | 15.7 |
| Other | 27 | 9.4 |
| Missing | 17 | 5.9 |
| **Age group (years)** | | |
| <=24 | 5 | 1.7 |
| 25-34 | 46 | 16.0 |
| 35-44 | 96 | 33.4 |
| 45-54 | 88 | 30.7 |
| 55+ | 25 | 8.8 |
| Missing | 27 | 9.4 |
| **Years in practice** | | |
| 0-5 | 26 | 9.1 |
| 6-10 | 42 | 14.6 |
| 11-15 | 41 | 14.3 |
| 16-20 | 38 | 13.2 |
| 21-30 | 70 | 24.4 |
| 30+ | 22 | 7.7 |
| Missing | 48 | 16.7 |
| **Gender** | | |
| Male | 60 | 20.9 |
| Female | 200 | 69.7 |
| Missing | 27 | 9.4 |
| **Ethnicity** | | |
| White | 182 | 63.4 |
| Black | 9 | 3.1 |
| Asian | 49 | 17.1 |
| Other | 12 | 4.2 |
| Not applicable | 4 | 1.4 |
| Missing | 31 | 10.8 |
| **Regularly work with long term condition patients** | | |
| Yes | 255 | 88.9 |
| No | 5 | 1.7 |
| Sometimes | 10 | 3.5 |
| Missing | 17 | 5.9 |
| **Clinical setting** | | |
| Within acute hospital setting | 199 | 69.3 |
| Outside hospital setting | 36 | 12.5 |
| Other | 18 | 6.3 |
| Missing | 34 | 11.8 |

## Activation of staff

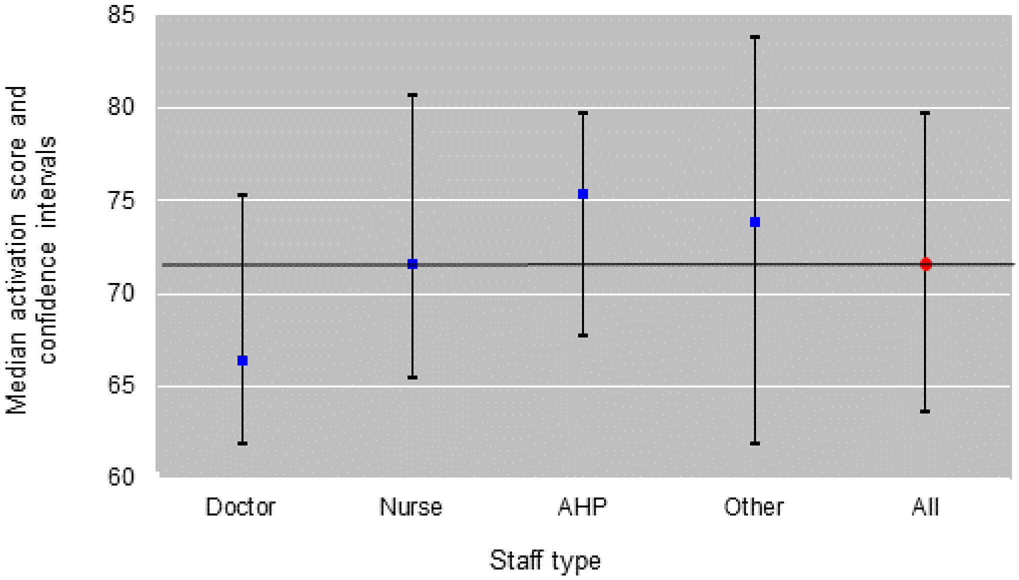
The median activation level of staff completing the questionnaire was 71.6 (mean 72.0) and 36% of staff were on the lowest activation level (figure 1).

**Figure 1 Percentage of staff by activation level**



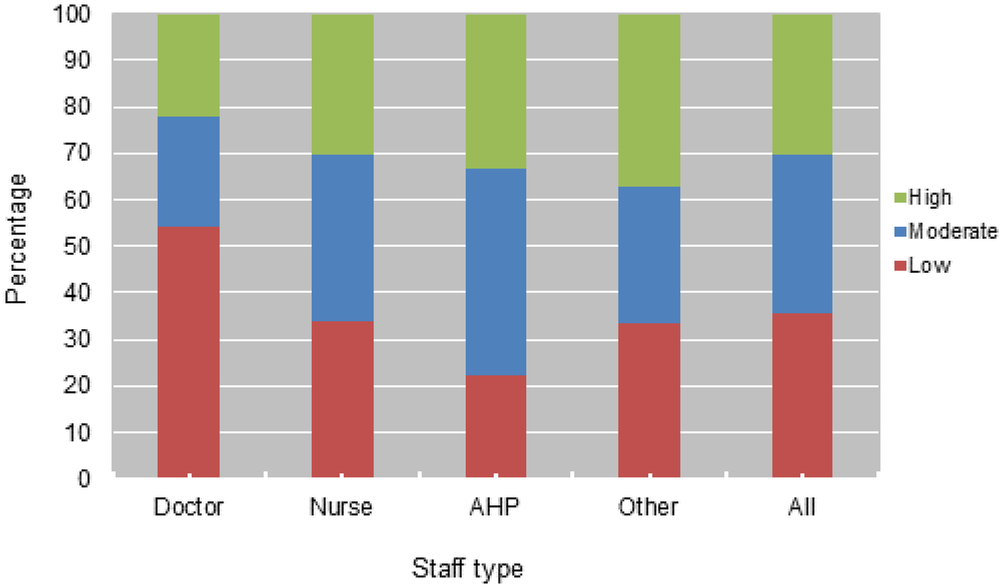
Median activation by staff type is shown in figure 2. Nursing staff and AHP were more activated than doctors, with a median activation score of 66 for doctors compared to 72 for nurses and 75 for AHP. There was evidence that this difference was statistically significant.

**Figure 2 Median activation score by staff type**



About 54% of doctors were on the lowest activation level compared to 34% for nurses and 22% for AHP (figure 3). AHPs had the largest proportion of moderately activated staff as well as the smallest proportion of staff on the lowest level of activation (figure 3).

**Figure 3 Percentage of staff type by activation level**



There was some variability in the median activation level by age group, with the highest activation level in younger staff members, aged ≤24 years (figure 4). Despite apparent differences in activation by age group, there was no evidence of a significant difference between age groups and activation. The biggest proportion of staff members on the lowest activation level were in age group 55+ years, followed by age group 35-44 years (figure 5). Younger members of staff (≤34 years) were mostly moderately activated

**Figure 4 Median activation score by age group**

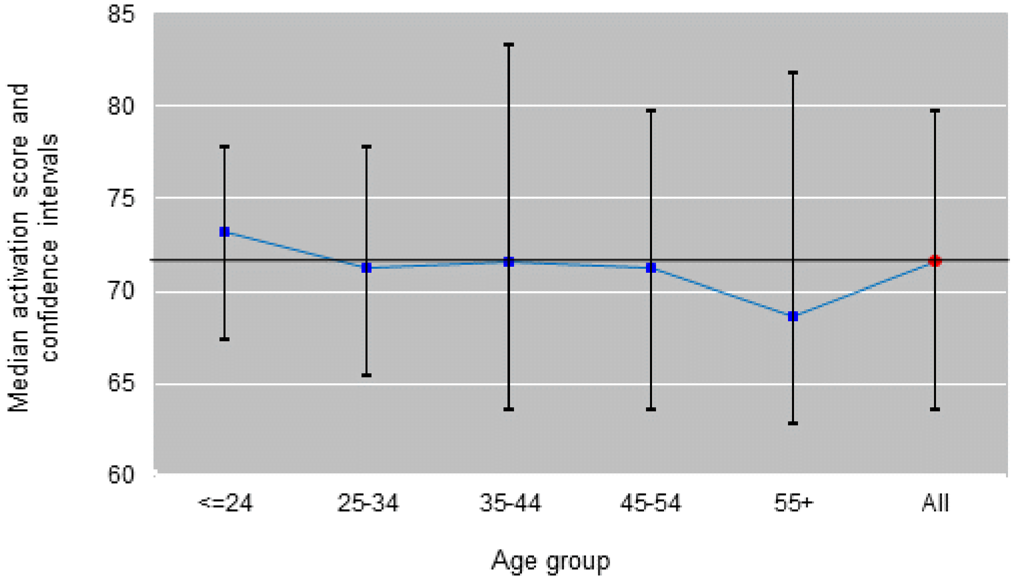
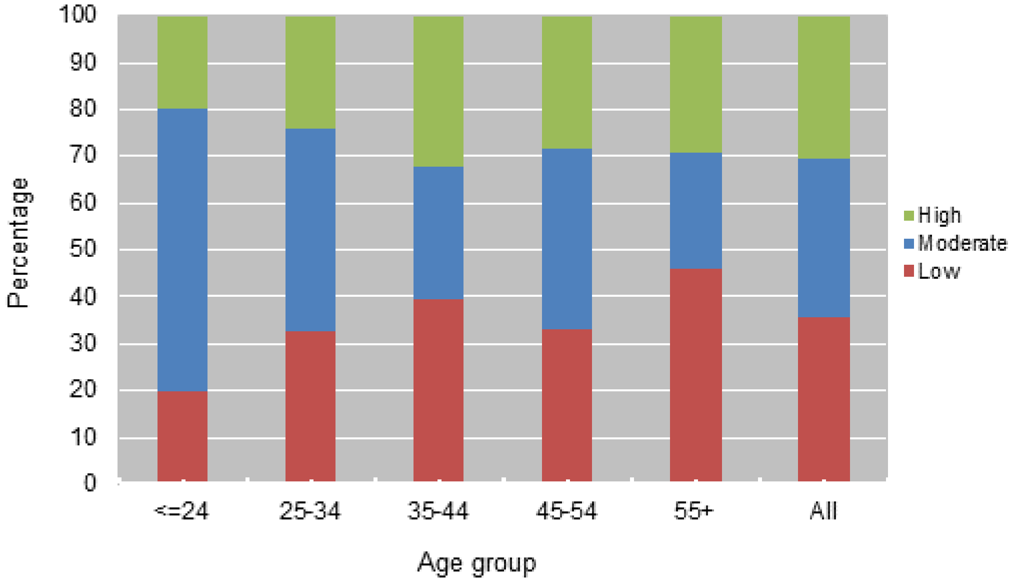
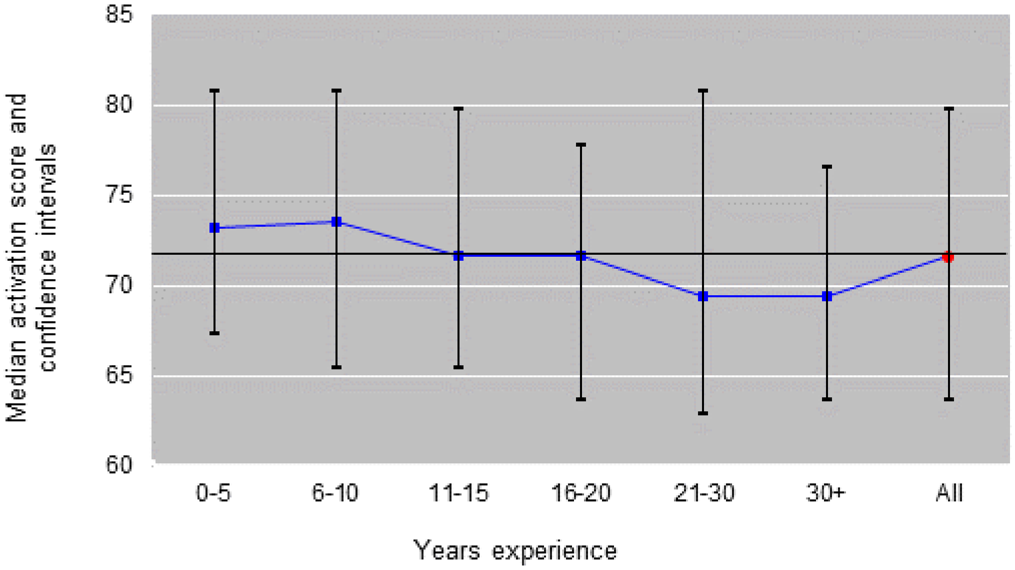


**Figure 5 Percentage of staff by activation level and age group**



Members of staff with less than 11 years of experience were more activated than those with more experience (11+ years) (figure 6). The highest median activation score was for staff with ≤5 and 6-10 years' of experience. Staff members with 21-30 and 30+ years of clinical experience had the lowest median activation score (figure 6). As the CS-PAM survey is self-reported, it is possible, for example, that more experienced staff are more self-critical of their activation status and score themselves lower.

**Figure 6 Median activation score by years' experience of staff**



The proportion of staff on the lowest level of activation increases as the number of years of experience increases (figure 7). Staff with experience between 21 to 30 years have a high proportion on the lowest as well as the highest levels of activation (figure 7).

**Figure 7 Percentage of staff by activation level and years' experience**

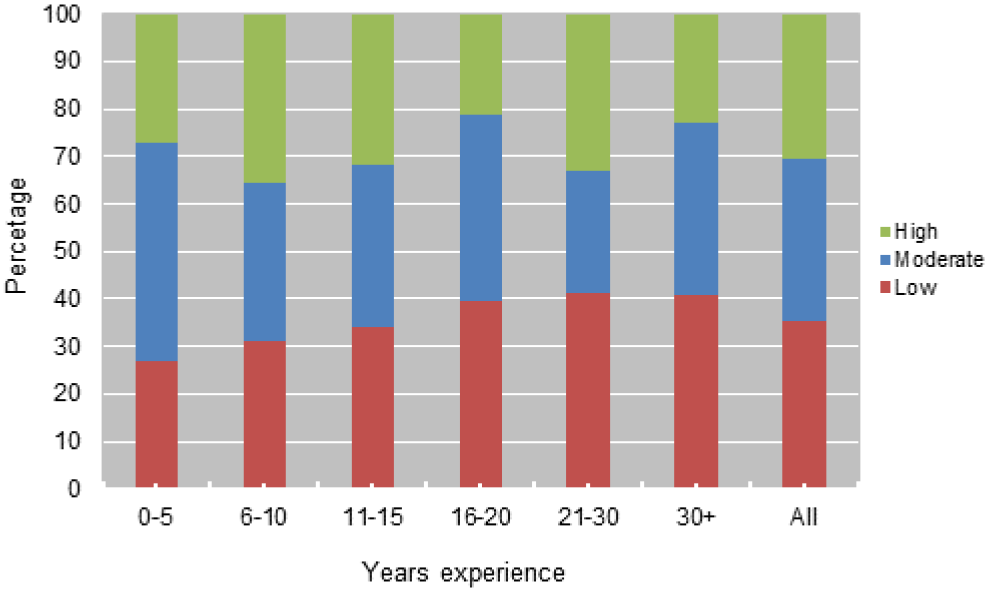
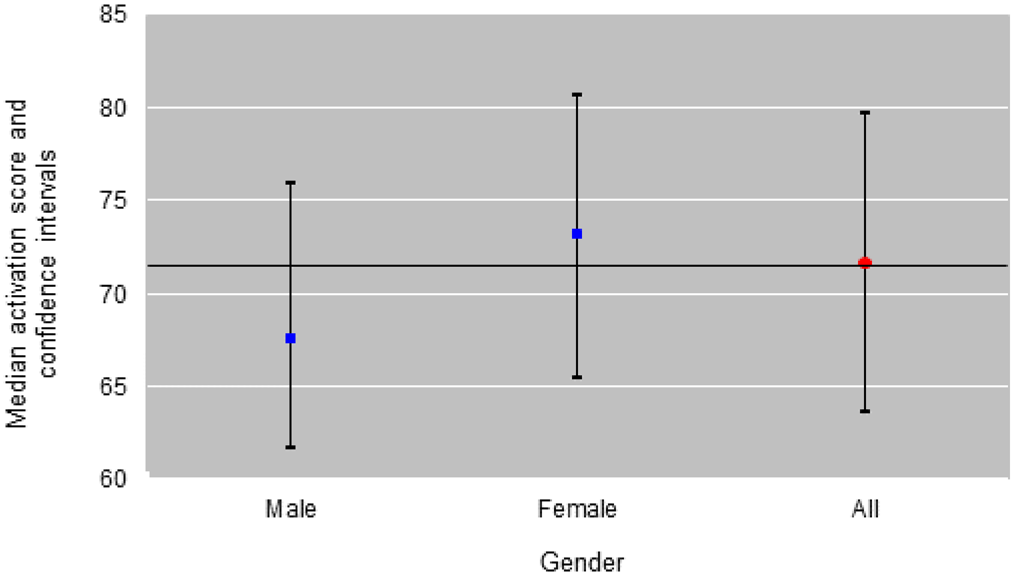
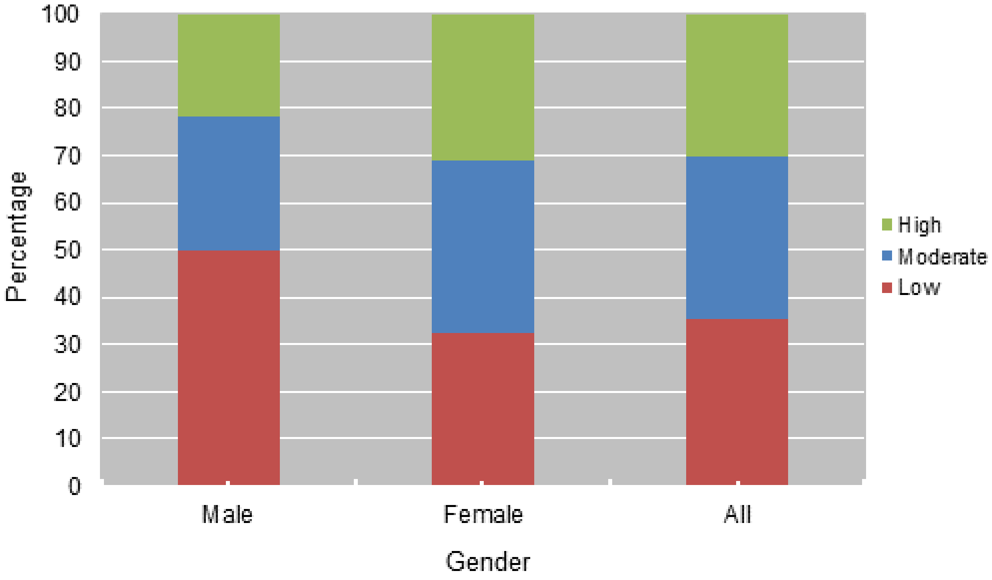


**Figure 8 Median activation score by gender**



Female members of staff have a much higher median activation score than male staff members (figure 8) and there is evidence that this difference is statistically significant. Fifty percent of male staff members were on the lowest activation level, whereas 68% of female members of staff were moderately or highly activated (figure 9).

**Figure 9 Percentage of staff by activation level and gender**



**Clinician support for patient activation by renal centre**

Across the 10 renal centres included in this report, the average number of staff per centre who would have been available to participate in this survey was estimated to be about 250. This includes all staff at a renal centre and not just health care professionals. This means that the estimated response rates were low, and varied from 2.8% to 30%, with an overall response rate of 14.3% for all respondents.

**Table 2 Staff numbers and exclusions by renal centre**

| Centre | Number of staff | Without identifiers | Exclusions | | Total included in report |
|---|---|---|---|---|---|
| | | | Activation score=100 | Incomplete surveys | |
| Centre 1 | 30 | 9 | 7 | 0 | 23 |
| Centre 2 | 58 | 45 | 11 | 0 | 47 |
| Centre 3 | 13 | 5 | 2 | 2 | 9 |
| Centre 4 | 75 | 18 | 0 | 10 | 65 |
| Centre 5 | 32 | 26 | 1 | 1 | 30 |
| Centre 6 | 7 | 2 | 1 | 0 | 6 |
| Centre 7 | 18 | 3 | 1 | 0 | 17 |
| Centre 8 | 16 | 5 | 1 | 0 | 15 |
| Centre 9 | 36 | 9 | 7 | 1 | 28 |
| Centre 10 | 20 | 4 | 3 | 0 | 17 |
| Missing centre | 53 | 40 | 7 | 16 | 30 |
| Total | 358 | 166 | 41 | 30 | 287 |

Table 2 shows the number and exclusion of staff by renal centre (see the methods sections for a discussion on the exclusion criteria). Feedback of CS-PAM results to individual staff members has been severely hampered by staff not providing identifiers when completing the survey. For instance 78% of staff in centre 2 who participated in the survey did not provide identifiers and will therefore not receive confidential individual feedback of their results.

## Table 3 Demographic characteristics of staff by renal centre

| Demographic characteristics | Renal centre (number of staff) | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Centre 1 | Centre 2 | Centre 4 | Centre 5 | Centre 7 | Centre 8 | Centre 9 | Centre 10 |
| All staff | 23 | 47 | 65 | 30 | 17 | 15 | 28 | 17 |
| Staff type | | | | | | | | |
| Doctor | 3 | 6 | 11 | 3 | 7 | 6 | 8 | 3 |
| Nurse | 13 | 27 | 36 | 17 | 6 | 6 | 13 | 10 |
| AHP | 6 | 5 | 10 | 10 | 3 | 3 | 3 | 1 |
| Other | 1 | 8 | 8 | 0 | 1 | 0 | 4 | 3 |
| Missing | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 |
| Age group (years) | | | | | | | | |
| <44 | 14 | 20 | 46 | 24 | 8 | 8 | 13 | 6 |
| 45+ | 9 | 22 | 17 | 6 | 7 | 7 | 15 | 9 |
| Missing | 0 | 5 | 2 | 0 | 2 | 0 | 0 | 2 |
| Years' experience | | | | | | | | |
| 0-10 | 6 | 12 | 18 | 12 | 3 | 3 | 10 | 2 |
| 11+ | 16 | 30 | 35 | 16 | 12 | 11 | 13 | 13 |
| Missing | 1 | 5 | 12 | 2 | 2 | 1 | 5 | 2 |
| Gender | | | | | | | | |
| Male | 5 | 12 | 17 | 3 | 6 | 6 | 3 | 2 |
| Female | 18 | 31 | 45 | 27 | 10 | 9 | 25 | 13 |
| Missing | 0 | 4 | 3 | 0 | 1 | 0 | 0 | 2 |

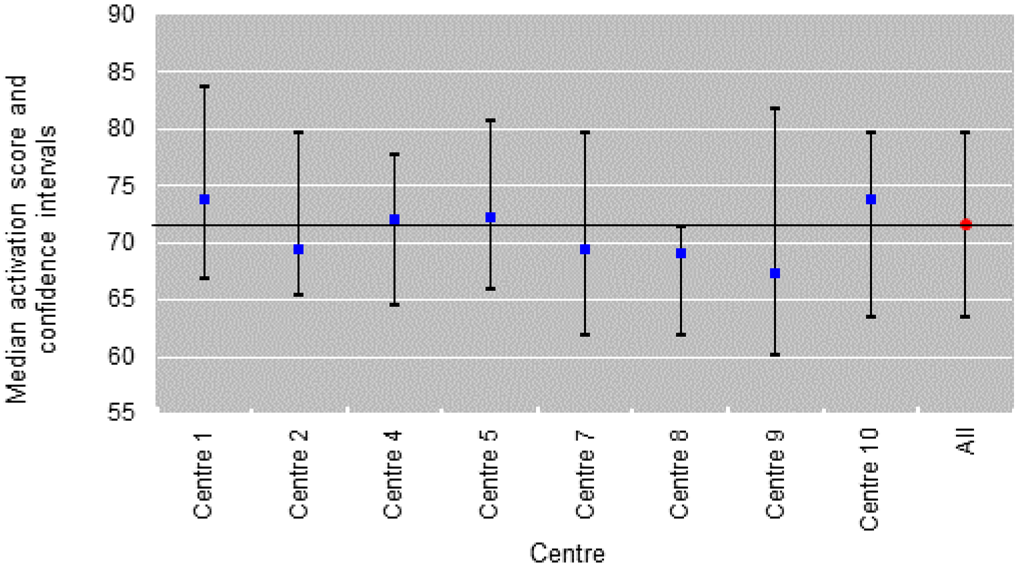
Due to low numbers (<10) of staff participating in centre 3 and centre 6, detailed information could not be provided.

Table 3 shows characteristics of staff that completed the survey by renal centre. All centre comparisons are unadjusted for staff characteristics such age, staff type, etc. In almost all renal centres, nursing staff completed most of the surveys (table 3).

Staff completing the survey across renal centres were mostly aged <44 years, had 11+ years of experience and the majority were female (table 3).

The median activation score by renal centre varied from 67.4 to 81.9 (figure 10). Confidence intervals were generally wide due to low numbers of staff completing the survey in some renal centres (see table 3). Despite apparent differences in the median activation score by renal centre, these differences were not statistically significant.

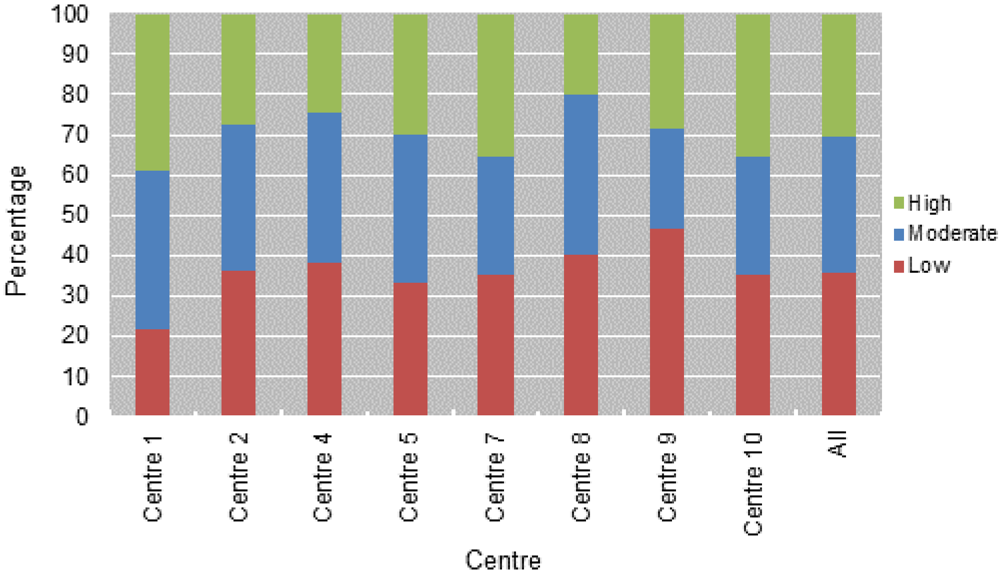
**Figure 10 Median activation score by renal centre**



The median activation score for centre 3 and centre 6 were not shown due to low numbers of staff (≤10) (figure 10).

The percentage of staff at each activation level (low, moderate and high) by renal centre is shown in figure 11. Staff on the lowest activation level ranged from 21.7% to as high as 46.4% at renal centre level. The percentage of staff in each renal centre on the highest activation level ranged from 20.0% to 66.0%.

**Figure 11 Percentage of staff by activation level and renal centre**

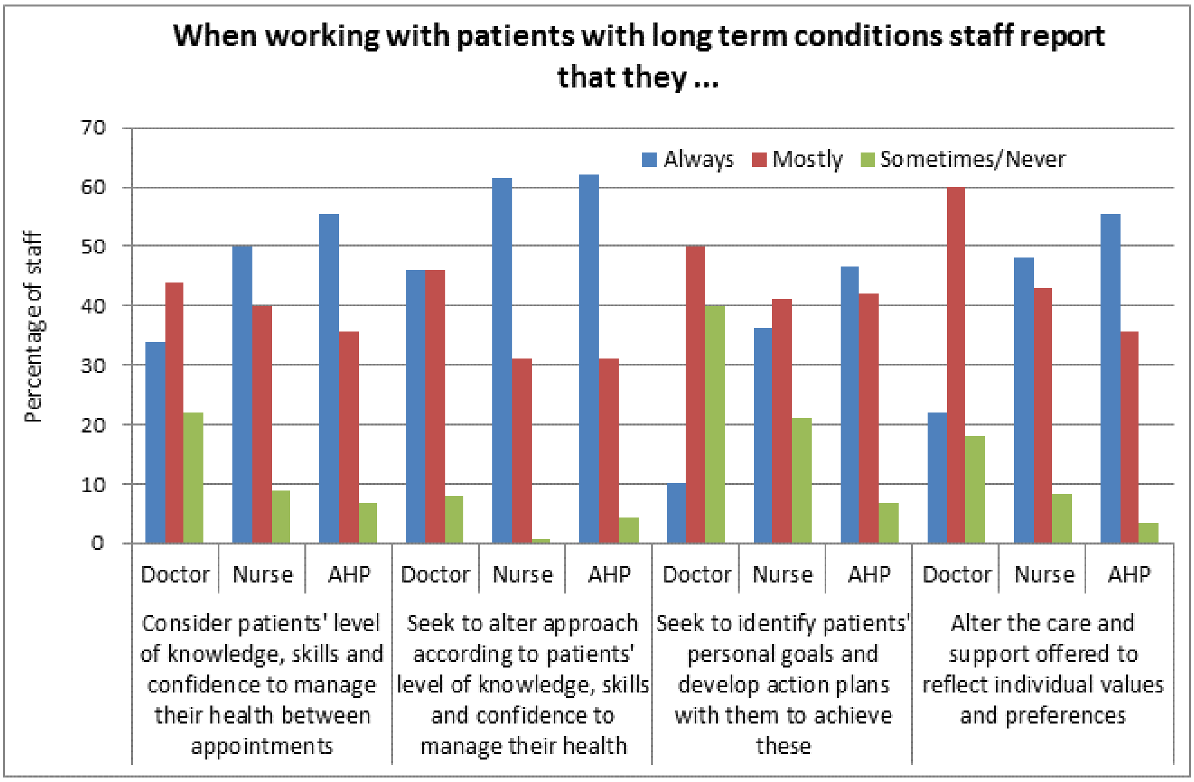


Activation levels for centre 3 and centre 6 were not shown due to low numbers of staff in some of the activation levels.

### Staff support for patient activation

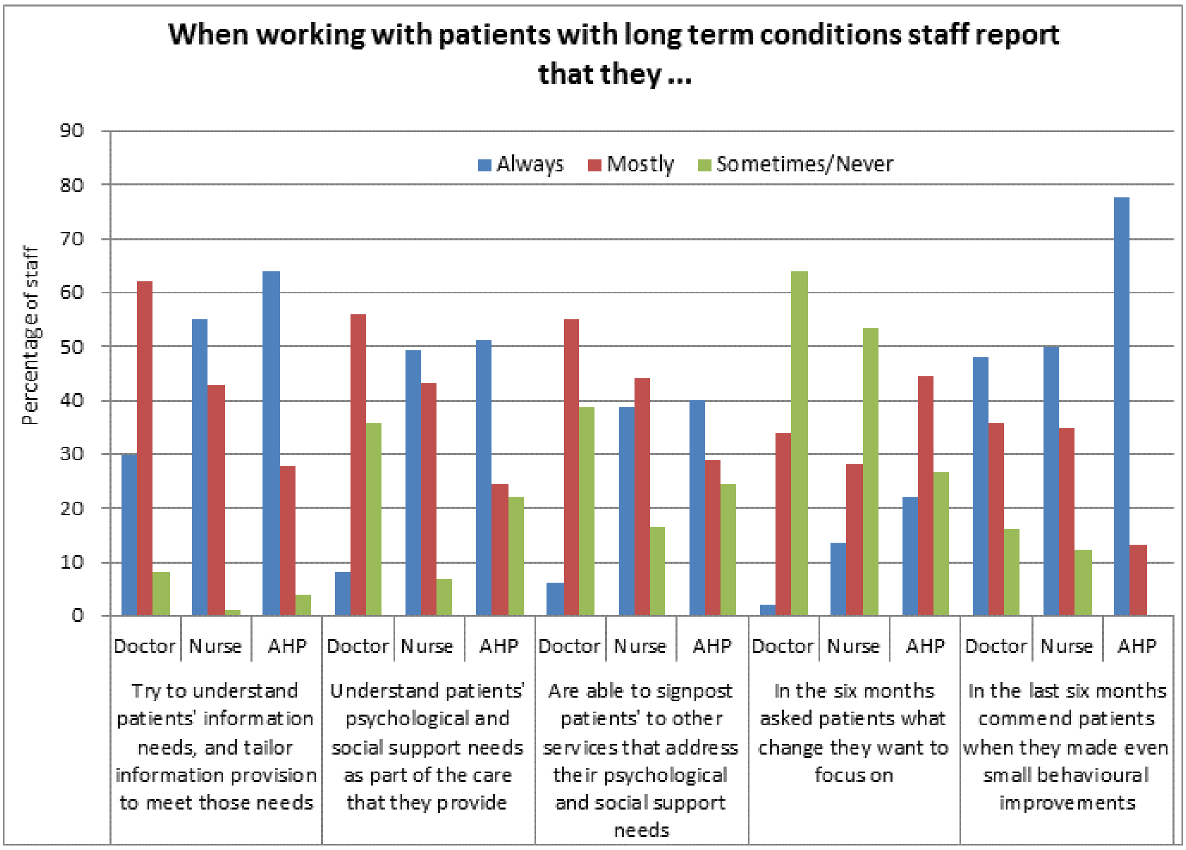
Figure 12 and 13 show how important staff view survey questions relating to behaviour.

**Figure 12 Responses to behaviour questions by staff type**



AHP followed by nurses are generally more likely than doctors to report that they ‘always’ engage in patient centred behaviour. A high proportion of doctors report that they ‘sometimes’ or ‘never’ engage in patient centred behaviour, for instance about 40% of doctors ‘sometimes’ or ‘never’ seek to identify patients’ personal goals and develop action plans with them to achieve these (figure 12). A very high proportion of doctors, nurses and AHP report that they ‘sometimes’ or ‘never’ in the last six months asked patients what change they want to focus on (figure 13). Twenty-two to 39% of doctors and AHP reported that they ‘sometimes’ or ‘never’ try to understand patients' psychological and social support needs as part of the care that they provide and signposting patients to other services that address their psychological and social support needs (figure 13).

**Figure 13 Responses to behaviour questions by staff type - continued**



Staff, irrespective of staff type, are most likely to change behaviours relating to:

- Altering their approach according to patients' level of knowledge, skills and confidence to manage their health (figure 12).
- Understanding the patients' information needs and tailoring information provision to meet those needs (figure 13).
- Commended patients when they made even small behavioural improvements (figure 13).

Questions relating to whether patients are able to function as a member of the care team were less likely to be supported by staff:

- Patient involvement as a full partner with the clinician in making decisions about their care was viewed by 7.5% of staff as ‘somewhat important’. Clinicians comprised the majority of staff with this view.

- About 5% of staff felt it was 'somewhat important' that patients want to know what procedures or treatments they will receive and why before the treatments or procedures are performed.

Questions relating to independent actions and judgements by patients were endorsed to an even lesser degree by staff:

- 11.1% of staff thought that it is 'somewhat' or 'not important' that patients believe that when all is said and done, they are the ones who are responsible for managing their health.
- The question 'how important is it to the clinician that patients know what each of their prescribed medications is for', was regarded as 'somewhat important' by 6.3% of staff.
- 6% of staff viewed the patients' ability to determine when they need to go to a health professional for care as 'somewhat' or 'not important' and doctors comprised the majority of staff with this view.
- 5.2% of staff reported that it is 'somewhat important' that patients are able to work out solutions when new situations or problems arise with their health condition.

Questions relating to the patient as an independent information seeker were least endorsed by staff:

- About 23% of staff believes that is it 'somewhat' or 'not important' that patients bring a list of questions (on paper or otherwise) when they come to the clinic, with doctors the majority of staff holding this view.
- And about 21% of staff indicated that it is 'somewhat' or 'not important' that patients look for trustworthy sources of information about their health and health choices, such as on the web, news stories, or books and the proportion of staff members with this view was similar between  doctors, nurses and AHP.

## Qualitative insights into clinicians support for patient activation

Many additional comments were given in the comments section of the survey, giving further information into why clinical teams felt less able to endorse certain behaviours.

Overall, teams were supportive of patients taking action and responsibility for their health although staff felt less able to endorse the following:

Respondents felt least able to support the concept that patients bring a list of questions (on paper or otherwise) when they come to the clinic, with doctors in the main holding this view.

Some clinicians welcomed patients preparing questions for clinic and felt it should be encouraged whilst others suggested that time within consultations was limited and was required to address clinical issues.

*‘Bringing a list of questions is important as it allows a more patient focused consultation. It also demonstrates that the patient has been thinking about their condition between appointments.’*

*‘Inappropriate referral/questions from patients can be time consuming to deal with.’*

The item suggesting that patients look for trustworthy sources of information about their health and health choices, such as on the web, news stories, or books also got relatively little support. On one hand staff supported patients gaining knowledge and education but acknowledged that not all patients would be active participants and shouldn’t be coerced to be so. Concerns were also raised about the availability of erroneous unfiltered information which can be more damaging than positive. The consensus was that careful signposting to trustworthy information was important but should then be discussed face to face in more detail.

*‘We have to respect it if some patients don't want involvement/information. Information from bad sources can be extremely damaging.’*

*'I think it is the job of the professional to advise patients to be cautious of some literature and internet information and direct to appropriate support or provide as relevant.'*

*'The key word is 'trustworthy' - clinicians have an important role in guiding patients to reliable sources.'*

Many staff found it difficult to endorse the belief that when all is said and done, patients are the ones who are responsible for managing their health.

They thought it was important to balance this against the individual choices, experiences and values of patients and felt that a 'one size fits all' approach was concerning. The majority of clinicians felt that it should be a partnership approach between the clinical teams and patients.

*'Patients need to be treated as individuals, so from a clinician's point of view it is important to understand that some patients will take full responsibility for their health, whilst some will want to share responsibility with the clinicians looking after them and some patients will not engage in the management of their health at all. It is important to recognise the different needs of individual patients.'*

*'People also need to know that they are not alone and solely responsible for their healthcare and that there is support available if they need it.'*

*'We have to recognise that for a large number of patients illness reduces their energy, confidence and self-esteem. Some may not have the personality or inclination to take these things on - others just are lazy or frightened and a lot of work is needed to get them to accept.'*

The item about the ability of patients to work out solutions when new situations or problems arise with their health condition(s) received relatively little support. Several reasons were given for this including patients being passive participants and concerns around the cognitive ability of individual patients to participate in their care.

*'In the sphere of my practice, it seems that the overwhelming majority of my patients behave as though their medical problems are in fact the doctors' problem.'*

*'I believe it is to the patients' advantage to be well educated about their condition however, not all patients have the ability to comprehend what is happening to their bodies and this should always be taken into consideration when speaking to our patients.'*

Clinicians, especially doctors gave relatively less support to the statement that 'patients want to be involved as full partners in their care and to know what procedures or treatments they will receive and why before the treatments or procedures are performed.' There were concerns about coercing patients into taking responsibility when perhaps they weren't ready and that patients need to be considered as individuals.

*'As clinicians we need to be able to respond to the level of engagement patients choose, pressuring them to do more is as bad as doing nothing in some ways'.*

*'This seems ideal but some patients don't always want to be a full partner or to have additional information and may ask family members to help or ask for a 'best' medical decision regarding care.'*

*'Not all patients want to know about the choices, options and treatments, it is very individual and if a patient has no interest there is no point trying to force them.'*

*'People with chronic health do not always have the emotional strength to be responsible fully for managing their health and clinicians needs to be aware of the impact of this.'*

Staff, especially doctors, had difficulty in endorsing the item that patients should have the ability to determine when they access a health care professional for care. On one hand it was thought that these sort of behaviours should be encouraged but with a degree of caution.

*'It is important to enable patients to manage their own care pathway as far as possible, to encourage them to take control of their choices. This also provides an understanding of their health needs and what support is available.'*

*'It has to be a sliding scale with clinicians taking the lead and then tailing off as patients become more knowledgeable. Left to their own devices patients can go in the wrong direction or be diverted by quick fixes.'*

## Perceived barriers to providing person centred care

### Resource constraints – Time

A significant barrier to providing more person centred care was the availability of time, especially within consultations.

*'This can only be done with detailed conversations which are very time consuming - so ideally would do with all patients at every visit, but realistically tend to focus on 1-2 patients in a clinic and then see other patients more quickly.'*

*'I think understanding of their disease and the short and long term consequences of their actions, is key. It means that clinical encounters become a dialogue as opposed to the clinician issuing a list of instructions. However, I find it challenging in the current clinical setting - with 15 minutes allotted for clinical reviews.'*

*'I am an expert but with full clinics time is limited in having these full and proper discussions with patients, truly exploring their desires, views, background, knowledge.'*

**Resource constraints – Lack of skills in clinical teams**

Another barrier that was identified was the lack of skills clinical teams felt they had in supporting patient centred care.

*'Use of motivational interviewing, understanding their personal support systems - family / friends, access to psychologists, peer support, other members of the clinical team.'*

*'More time, training, funding for training would help!'*

*'In renal I find it hard to let the patient set the agenda.'*

*'Whilst health care professionals are available to meet psychological and social needs there is always a desire to delegate this to nurses and doctors when they don't have the skill set to do this.'*

*'I'd like to think I try hard to tailor my approach but I am not sure how often this is true. It can be difficult to achieve this in a pure clinical setting and often needs the help of the multi-disciplinary team (MDT) and time to clarify the picture of the whole person.'*

*'I must try to celebrate success more - I have a tendency to focus on the problems. Patients do tell me that they would like to have more encouragement for the progress that they have made with phosphate - rather than being beaten up for not achieving the target.'*

*'Personal goals may be very different from clinical goals, so whilst they need to be considered, I think there are some things that healthcare professionals should not be involved in. There may be limitations as to what we can do with limited resources.'*

*'I always try to base my plan on the patient's values, beliefs and diet etc. I however may see a patient where their priority may be one issue but my priority may be biochemistry etc. I sometimes need to highlight this to the patient.'*

### Resource constraints – Lack of support services

A further barrier that was cited was lack of support services available, especially psychologists and social workers. This in turn had an impact upon time available to clinicians within consultations.

> *'There is a lack of psychological support available to this centre. Not all of our resources are suitable for all patients but lack of staffing means that these are slow to be developed/obtained.'*

> 'We have very limited psychosocial support - and identifying needs is therefore not always very helpful.'

> *'We do not have a clinical psychologist or renal support worker. We tend to take this hat on too.'*

### Resource constraints – Ability and willingness of patients

Ability and willingness of patient to take control of their care was cited by several clinicians as being a barrier and felt that this needed to be carefully balanced.

> *'I feel sometimes patients are sometimes willing to make decisions that may help themselves in the short term which is not always the best in the long-term. They are responsible for their own health but also need advice and support.'*

> *'It's clearly easier, more satisfying, and associated with better biological as well as psychological outcomes to deal with more activated patients and patients with higher degrees of literacy and health literacy; whether or not patients lower down the scale can effectively be moved up the scale by coaching, or any other action on the part of health professionals, I'm not so sure.'*

## Summary and implications

This report gives a snapshot of clinical attitudes and support for patient activation across 10 renal centres in cohort 1 of Transforming Participation in the CKD programme for the CS-PAM survey. The aim of this exercise was to gain an idea of the landscape of staff attitudes and beliefs to person centred care within each renal centre with the intention that once fed back acts as a catalyst for change.

The report is not about judgement but for organisations and teams to use it as a tool to reflect on their attitudes and practices towards supporting patients in taking a more active role in their health and care.

CS-PAM has been shown to reliably assess clinician belief and attitude towards patients managing their own health care [3], but it has to be highlighted that the survey measures self-reported clinical attitudes and beliefs and not actual behaviour when treating patients with CKD.

With only 30% of staff scoring as highly activated and with a wide individual CS-PAM score range of 22.6-90.6, changes are required at local level, although within this range there is a wealth of learning to be shared amongst centres. The variability in support for patient activation by staff seen in this research, was also reported in the study by Hibbard and colleagues and in the more recent NHS England CS-PAM report [3, 4].

Response rates across the 10 renal centres based on an estimated total workforce varied greatly from 2.8% to 30% with a response rate of 14.3% for all respondents. A response rate of 35% for UK and 81% for US staff was reported in the CS-PAM development study [3], but the NHS England CS-PAM report did not publish response rates [4].

Twenty-one percent of respondents in this research were male compared to 49% and 56% in other CS-PAM studies [3, 4]. More than 60% of respondents were in age group 35-44 and 45-54 and this was similar to other CS-PAM research [3, 4]. The ethnic breakdown was similar to the NHS England CS-PAM report [4] where 60% of respondents were of White ethnicity compared to 63% in this report. The majority of respondents had 21+ years of clinical experience; these results were similar to the NHS England CS-PAM report, whereas research by Hibbard and colleagues reported that the majority of staff had 11-15 years' of clinical experience [3, 4]. A much lower percentage of respondents were doctors (17%) than in other studies where 44% and 90% of staff were doctors [3, 4].

The mean activation score of 72.0 (range 22.6-90.6, median=71.6) was higher than the 69.0 (range 10.0-100) reported in the study by Hibbard and colleagues and similar to the mean activation score of 72.4 (range 36.4-100) in the NHS England CS-PAM report, indicating that clinical support for patient activation has not changed substantially over the last 6 years [3, 4].

There was evidence of a significant difference in the support for patient activation between genders and staff type: female staff members were more activated than males, nurses and AHP were more activated than doctors. There was no significant difference found between activation and age and years' clinical experience. Although there was no evidence of a statistical difference in the study by Hibbard and colleagues, younger staff and those with <20 years' of experience were more activated, activation was similar between staff types and activation by gender was not reported [3]. There was no significant difference in activation between age groups, gender or region in the NHS England CS-PAM report, but evidence of a significant difference was seen by staff type, where nurses were more activated (75.9) than doctors (70.1) and AHP (71.7) [4].

An analysis of individual survey questions showed that staff were more likely to support behaviour and practice relating to understanding the patients' information needs and tailoring information provision to meet those needs, commending patients when they made behavioural improvements and altering their approach according to the patients' level of knowledge, skills and confidence.

There was strong support from staff that patients should follow medical advice and this result was also reported in other studies [3, 4]. Staff were less likely to support questions relating to whether patients are able to function as a member of the care team. Independent actions and judgements by patients were supported to a lesser degree by staff and least supported was patients seeking information independently. Similar findings were reported in the CS-PAM development paper and the NHS England CS-PAM report [3, 4].

Medical staff are shown as being least able to endorse and support person centred care which has the potential to impact upon the team. Doctors are invariably the leads within a centre and exercise influence and power within a team.

It is clear from the additional comments that there are several barriers to delivering person centred care which mainly focus on systems and resource. Time was highlighted as a significant barrier alongside lack of support staff such as psychology and social worker support. It was felt that additional skills relating to person centred care would enhance this approach.

## Limitations

There are some limitations in this research. The low number of staff completing the survey in some of the 10 renal centres taking part in cohort 1 (see tables 1 to 3), limits the reporting of results at centre level as the number of respondents in some categories were too small and could result in the identification of respondents. It also limits the usability of the CS-PAM information at centre level as the generalisability of results for a renal centre where only a few members of staff completed the survey is questionable. Due to the low number of respondents at centre level, more detailed centre level reports will only be possible in 2 renal centres. An increase in the number of respondents at centre level is needed to report meaningful statistics back to centres and for results to useful in affecting clinical change.

Centres did not readily engage in participating in CS-PAM. Several centres have subsequently suggested that it was too soon in the project to understand the relevance and their role. The message about the TP-CKD programme and person centred care had not been spread wider than the initial working group in several centres and this is potentially reflected in the participant numbers.

In one centre the point was raised that not all staff can access computers at work and were therefore unable to complete the survey electronically. Once this had been highlighted paper copies of the survey were provided with a subsequent increase in participation.

Several members of staff said that the request to participate in the electronic survey was buried or embedded in an email that was then filed and not returned to. It wasn't seen as a priority until a visit by the person centred care facilitator discussed the reasons for doing it as part of the bigger TP-CKD programme.

The message that the completion of the survey was confidential and survey results will only be shared with the individual staff member, who completed the survey, may not have been clearly communicated. This would have had a potential impact on the survey response rate. The message of confidentiality of individual surveys has to be highlighted prior to the start of the cohort 2 CS-PAM collection.

Response rates were low with big differences between renal centres and it is therefore likely that responses are biased. Staff completing the survey are self-selective, and it is not known whether respondents are representative of the staff in each renal centre and of staff working in the wider kidney community. If there is bias in the results it will possibly be more towards staff that are activated and support person centred care completing the survey.

## Conclusions and next steps

The findings give a snapshot across 10 renal centres of current attitudes of the staff surveyed. This provides an insight that will be built upon across the programme by facilitating teams on developing their support for patient activation. Many who were surveyed are broadly supportive of patient activation, although there are still a range of attitudes identified. Ultimately it is hoped that teams will reach an understanding that a part of their job is supporting the engagement of the patient as an active partner in their care and treatment.

In order to challenge the current roles and relationships, behaviours and develop partnerships, health care professionals will need to be supported to develop new skills.

The report also highlights significant structural barriers which sometimes prevent teams from practicing a patient centred care approach and these also need to be considered when looking at different ways of supporting person centred care.

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2. Wanless, D., Securing our Future Health: Taking a Long-Term View, H. Treasury, Editor. 2002.
3. Hibbard, J.H., et al., The development and testing of a measure assessing clinician beliefs about patient self-management. Health Expectations, 2009. 13: p. 65-72.
4. How much do clinicians support patient activation? 20 November 2015, NHS England.
5. Hibbard, J.H., et al., Development and testing of a short form of the patient activation mesure. Health Services Research, 2005. 40 (6 Pt 1):1918-1930.
6. Hibbard, J.H., et al., Development of the Patient Activation Measure (PAM): Conceptualizing and Measuring Activation in Patients and Consumers. Health Services Research 2004. 39:4 , Part I (August 2004).

### Acknowledgments

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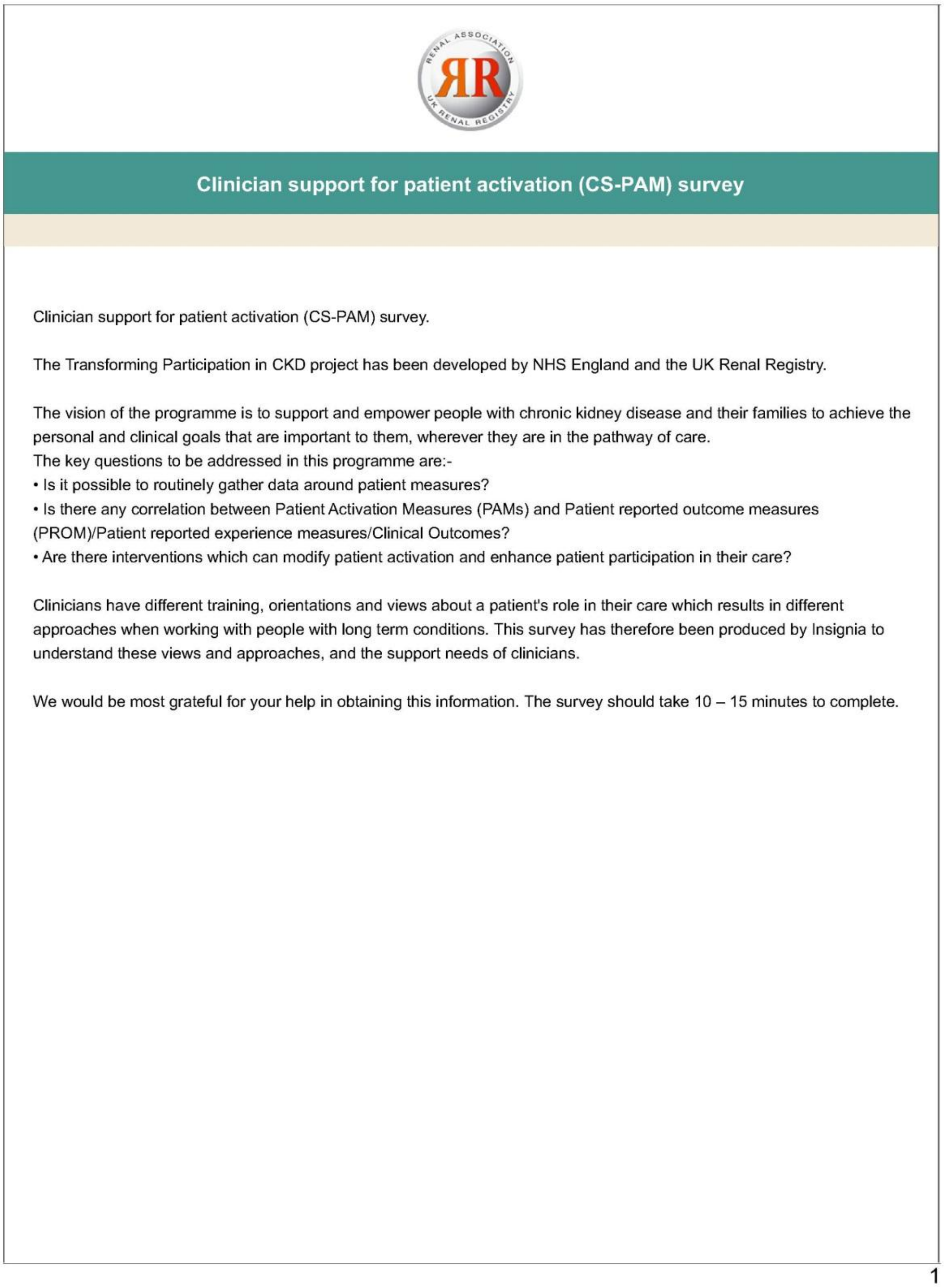
Paul Bristow
Peter Naish
Ramla Mumtaz
Rob Elias
Sarah Evans

## Appendix A – Copy of the Clinician Support for Patient Activation Measure (CS-PAM) Survey



### Clinician support for patient activation (CS-PAM) survey

Clinician support for patient activation (CS-PAM) survey.

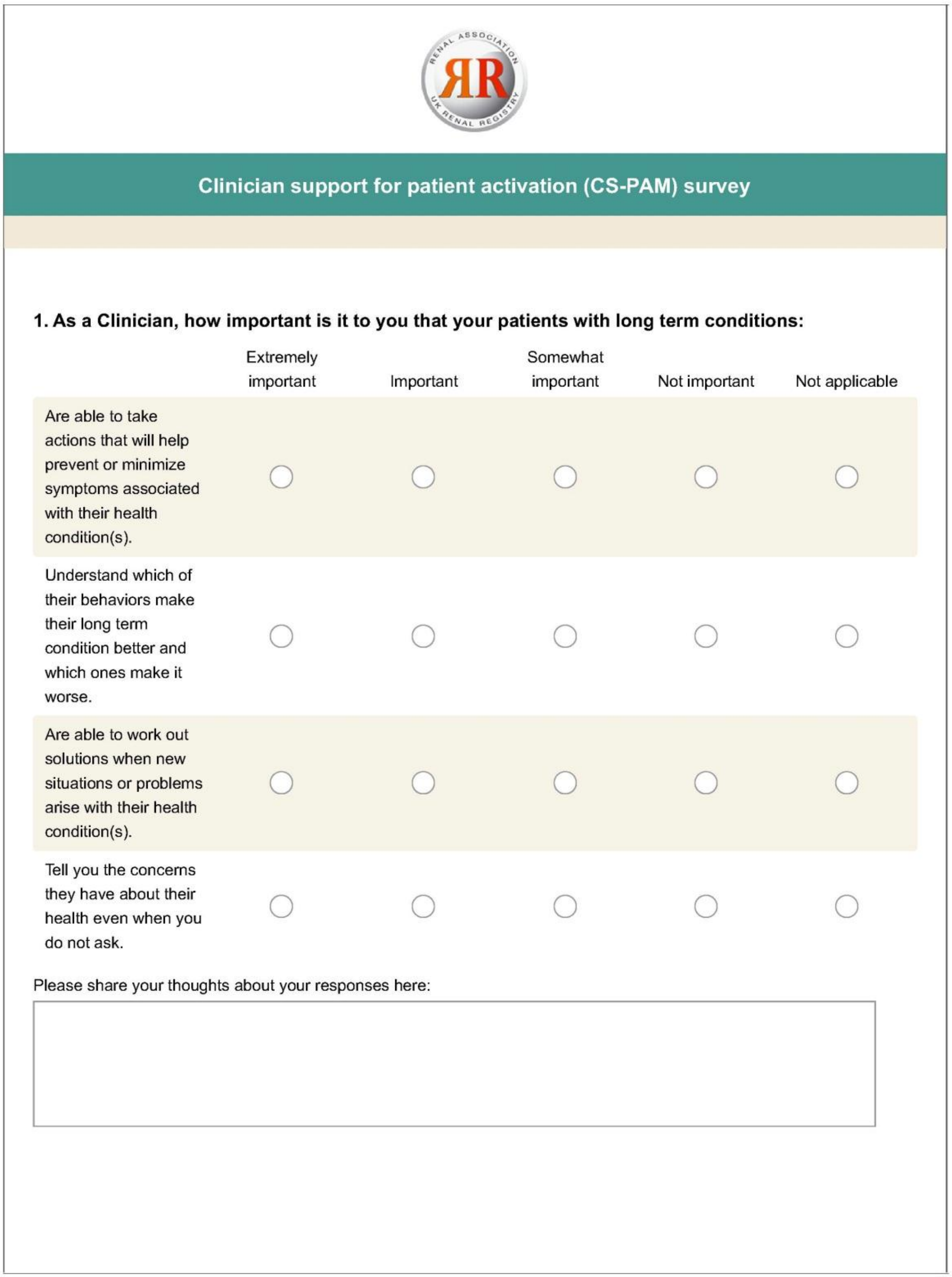
The Transforming Participation in CKD project has been developed by NHS England and the UK Renal Registry.

The vision of the programme is to support and empower people with chronic kidney disease and their families to achieve the personal and clinical goals that are important to them, wherever they are in the pathway of care.
The key questions to be addressed in this programme are:-
- Is it possible to routinely gather data around patient measures?
- Is there any correlation between Patient Activation Measures (PAMs) and Patient reported outcome measures (PROM)/Patient reported experience measures/Clinical Outcomes?
- Are there interventions which can modify patient activation and enhance patient participation in their care?

Clinicians have different training, orientations and views about a patient's role in their care which results in different approaches when working with people with long term conditions. This survey has therefore been produced by Insignia to understand these views and approaches, and the support needs of clinicians.

We would be most grateful for your help in obtaining this information. The survey should take 10 – 15 minutes to complete.

1

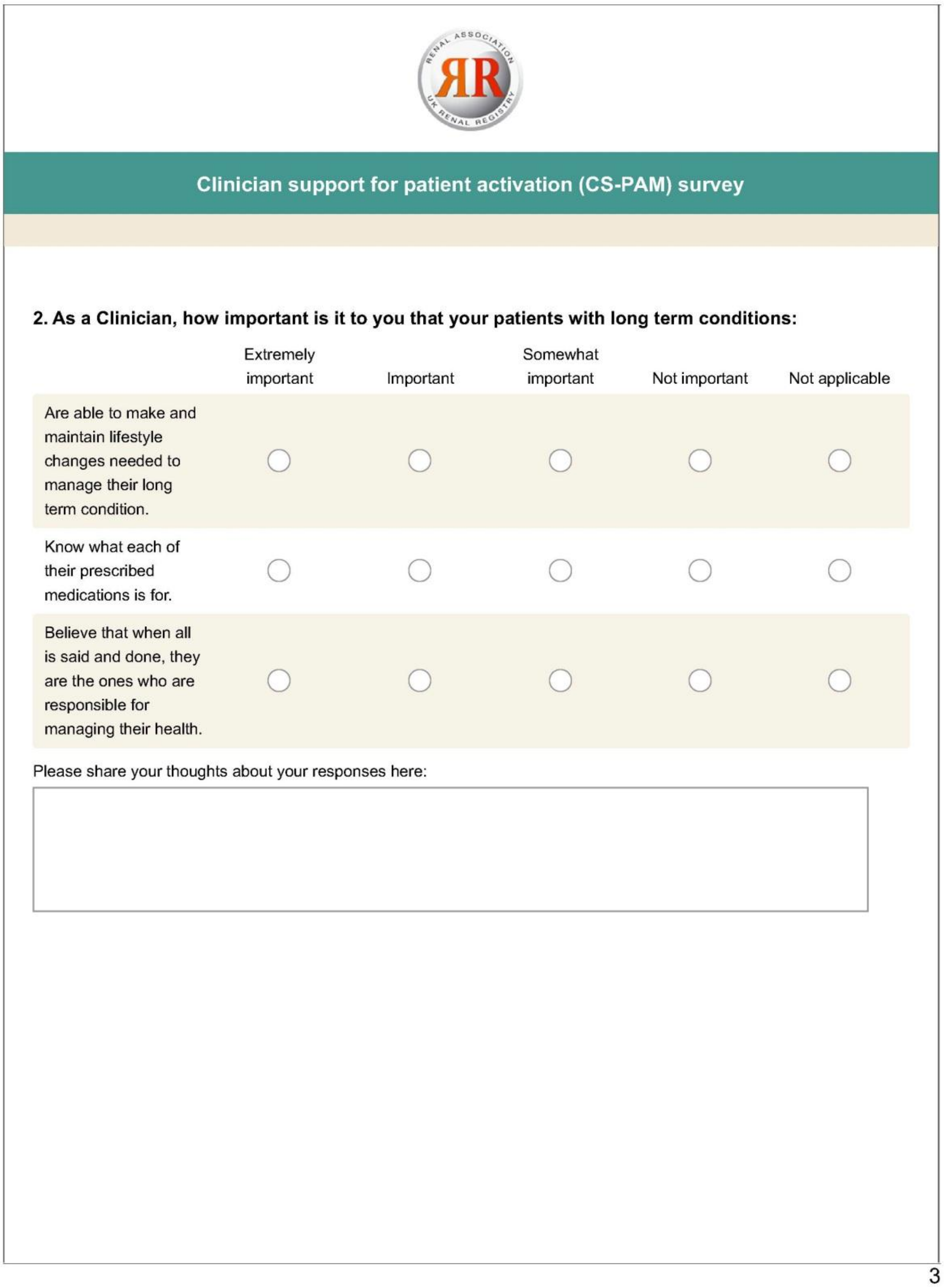


## Clinician support for patient activation (CS-PAM) survey

**1. As a Clinician, how important is it to you that your patients with long term conditions:**

| | Extremely important | Important | Somewhat important | Not important | Not applicable |
|---|---|---|---|---|---|
| Are able to take actions that will help prevent or minimize symptoms associated with their health condition(s). | ○ | ○ | ○ | ○ | ○ |
| Understand which of their behaviors make their long term condition better and which ones make it worse. | ○ | ○ | ○ | ○ | ○ |
| Are able to work out solutions when new situations or problems arise with their health condition(s). | ○ | ○ | ○ | ○ | ○ |
| Tell you the concerns they have about their health even when you do not ask. | ○ | ○ | ○ | ○ | ○ |

Please share your thoughts about your responses here:

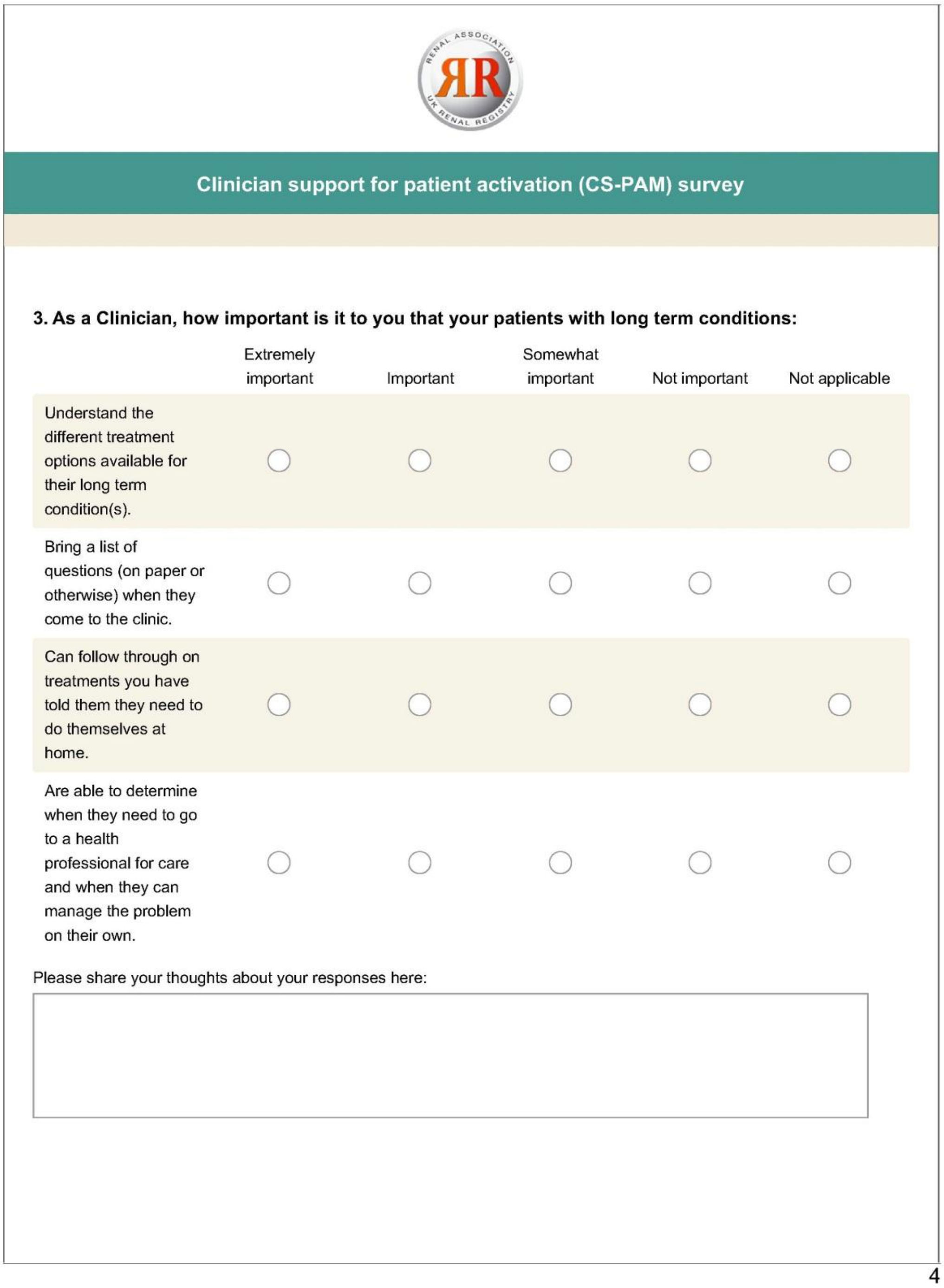


## Clinician support for patient activation (CS-PAM) survey

**2. As a Clinician, how important is it to you that your patients with long term conditions:**

| | Extremely important | Important | Somewhat important | Not important | Not applicable |
|---|---|---|---|---|---|
| Are able to make and maintain lifestyle changes needed to manage their long term condition. | ○ | ○ | ○ | ○ | ○ |
| Know what each of their prescribed medications is for. | ○ | ○ | ○ | ○ | ○ |
| Believe that when all is said and done, they are the ones who are responsible for managing their health. | ○ | ○ | ○ | ○ | ○ |

Please share your thoughts about your responses here:



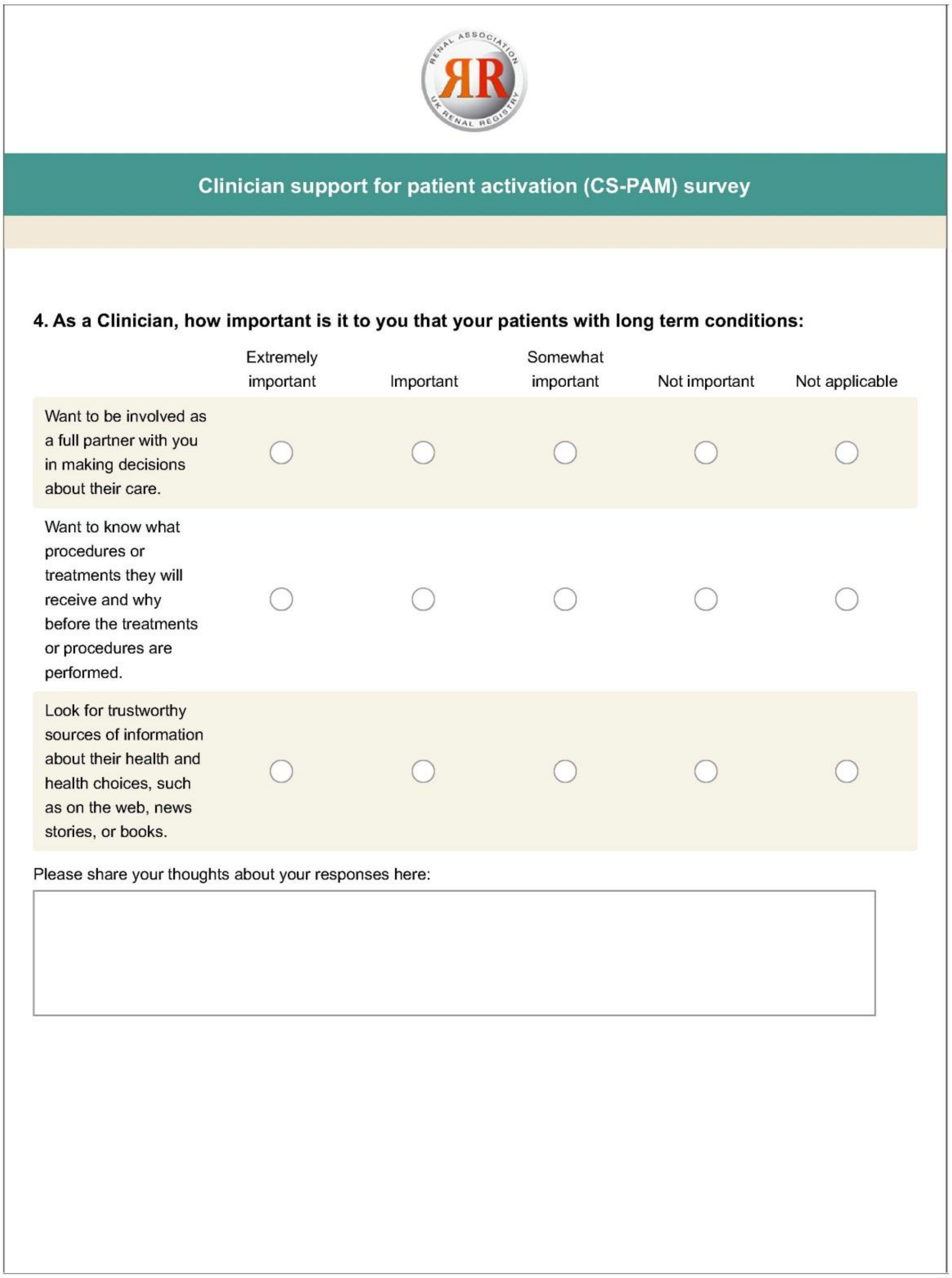
## Clinician support for patient activation (CS-PAM) survey

**3. As a Clinician, how important is it to you that your patients with long term conditions:**

| | Extremely important | Important | Somewhat important | Not important | Not applicable |
|---|---|---|---|---|---|
| Understand the different treatment options available for their long term condition(s). | ○ | ○ | ○ | ○ | ○ |
| Bring a list of questions (on paper or otherwise) when they come to the clinic. | ○ | ○ | ○ | ○ | ○ |
| Can follow through on treatments you have told them they need to do themselves at home. | ○ | ○ | ○ | ○ | ○ |
| Are able to determine when they need to go to a health professional for care and when they can manage the problem on their own. | ○ | ○ | ○ | ○ | ○ |

Please share your thoughts about your responses here:

4



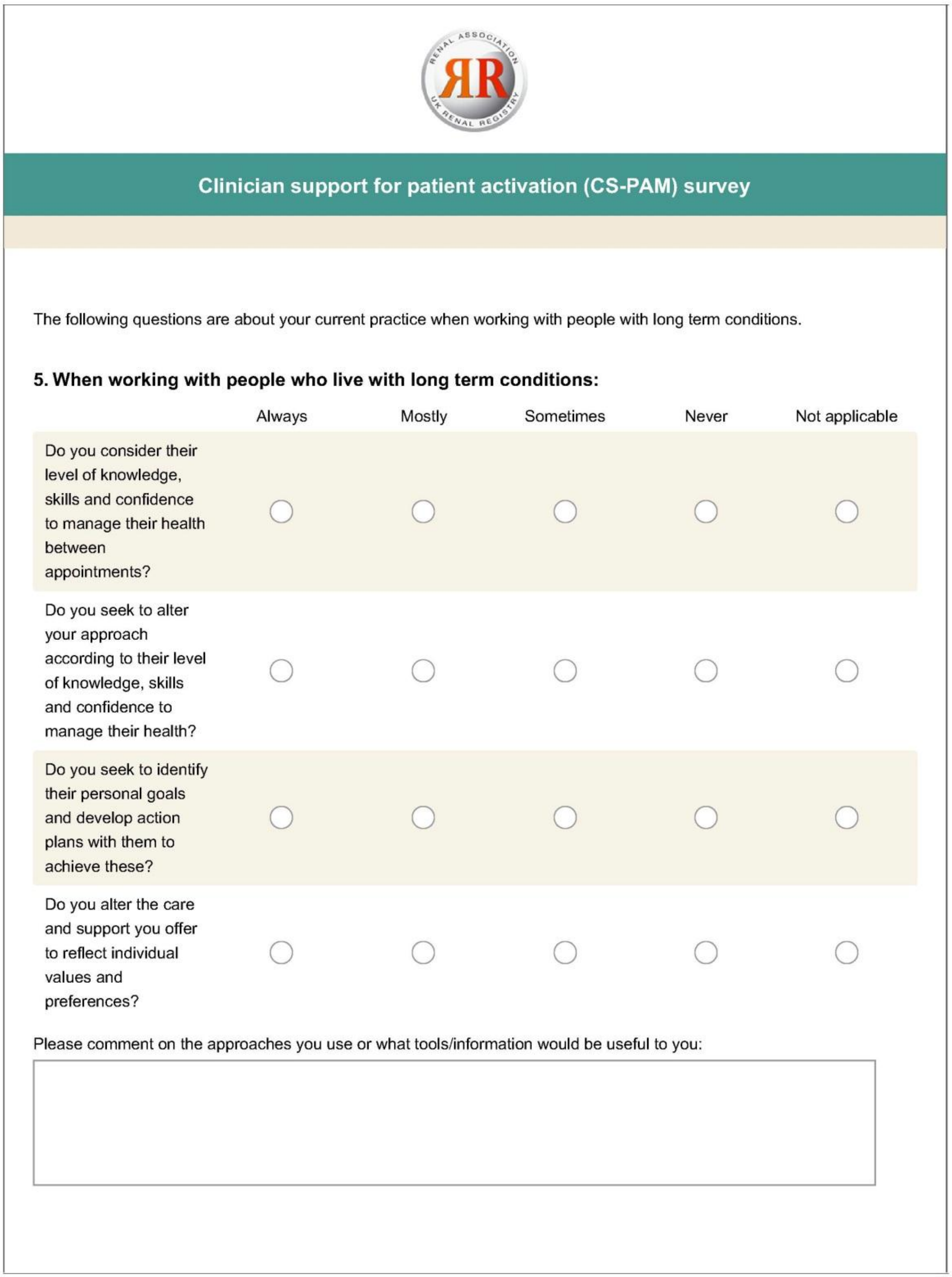
## Clinician support for patient activation (CS-PAM) survey

**4. As a Clinician, how important is it to you that your patients with long term conditions:**

| | Extremely important | Important | Somewhat important | Not important | Not applicable |
|---|---|---|---|---|---|
| Want to be involved as a full partner with you in making decisions about their care. | ○ | ○ | ○ | ○ | ○ |
| Want to know what procedures or treatments they will receive and why before the treatments or procedures are performed. | ○ | ○ | ○ | ○ | ○ |
| Look for trustworthy sources of information about their health and health choices, such as on the web, news stories, or books. | ○ | ○ | ○ | ○ | ○ |

Please share your thoughts about your responses here:

5



## Clinician support for patient activation (CS-PAM) survey

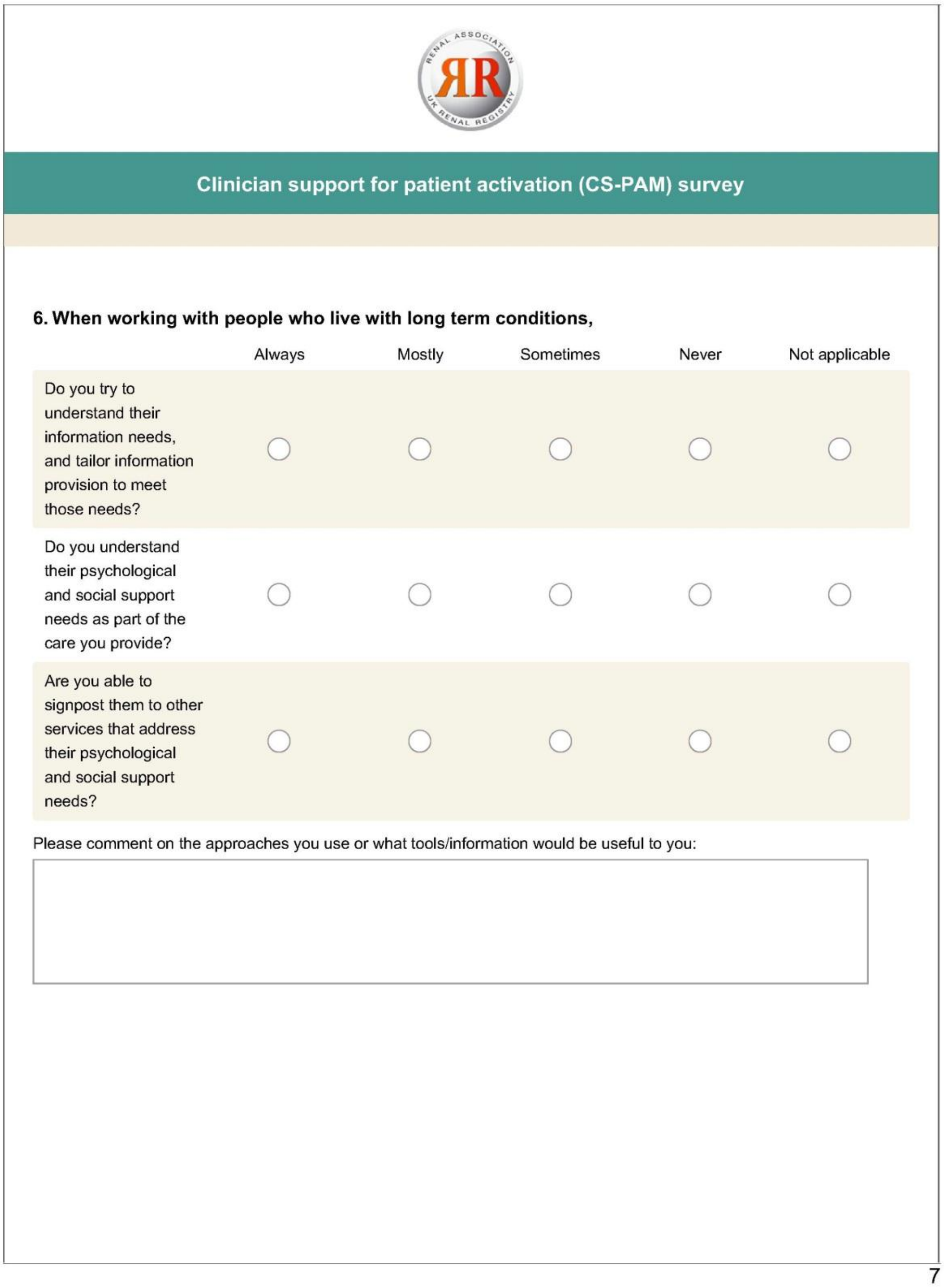
The following questions are about your current practice when working with people with long term conditions.

**5. When working with people who live with long term conditions:**

| | Always | Mostly | Sometimes | Never | Not applicable |
|---|---|---|---|---|---|
| Do you consider their level of knowledge, skills and confidence to manage their health between appointments? | ○ | ○ | ○ | ○ | ○ |
| Do you seek to alter your approach according to their level of knowledge, skills and confidence to manage their health? | ○ | ○ | ○ | ○ | ○ |
| Do you seek to identify their personal goals and develop action plans with them to achieve these? | ○ | ○ | ○ | ○ | ○ |
| Do you alter the care and support you offer to reflect individual values and preferences? | ○ | ○ | ○ | ○ | ○ |

Please comment on the approaches you use or what tools/information would be useful to you:

6



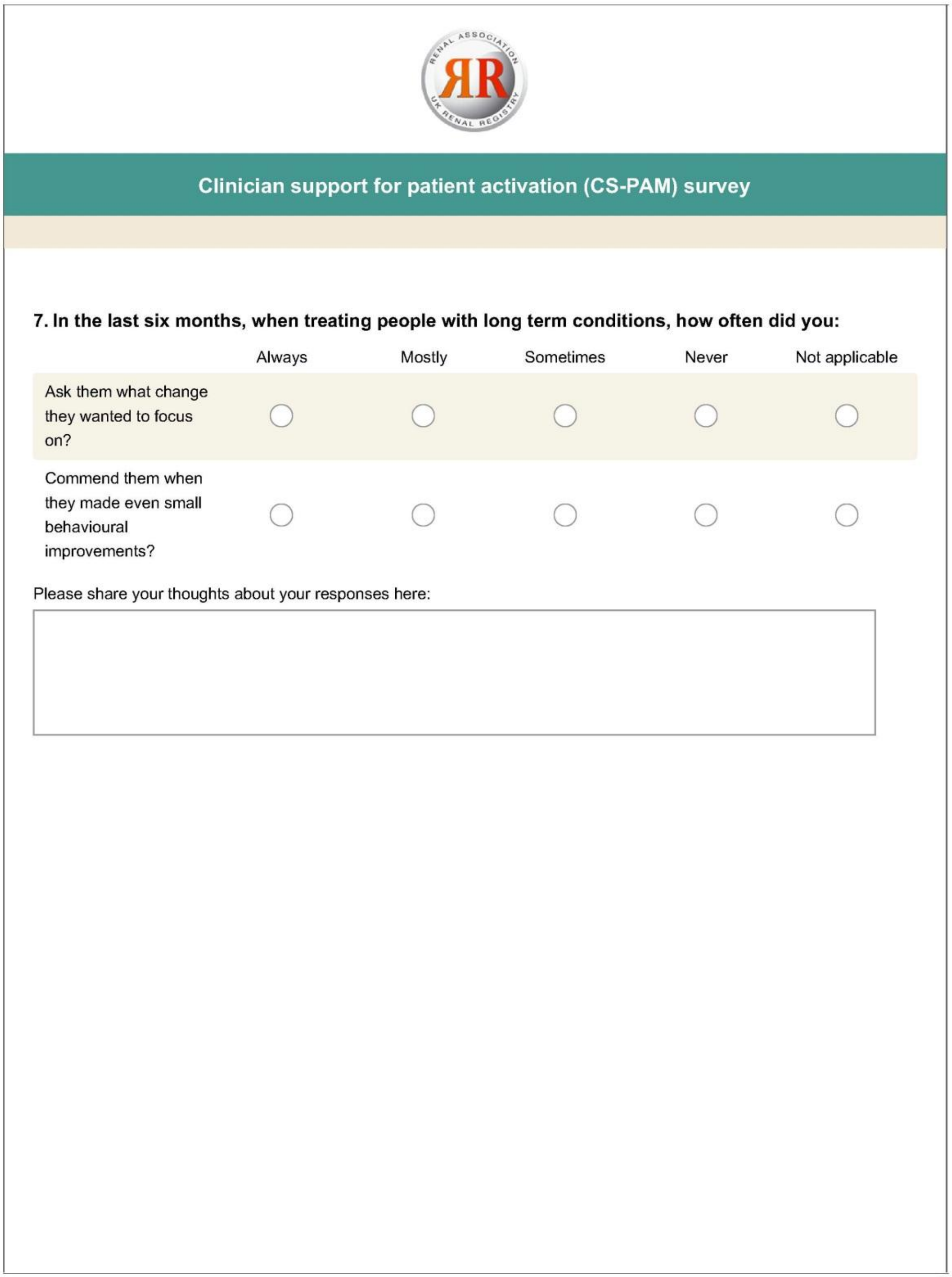
## Clinician support for patient activation (CS-PAM) survey

**6. When working with people who live with long term conditions,**

| | Always | Mostly | Sometimes | Never | Not applicable |
|---|---|---|---|---|---|
| Do you try to understand their information needs, and tailor information provision to meet those needs? | ○ | ○ | ○ | ○ | ○ |
| Do you understand their psychological and social support needs as part of the care you provide? | ○ | ○ | ○ | ○ | ○ |
| Are you able to signpost them to other services that address their psychological and social support needs? | ○ | ○ | ○ | ○ | ○ |

Please comment on the approaches you use or what tools/information would be useful to you:

7

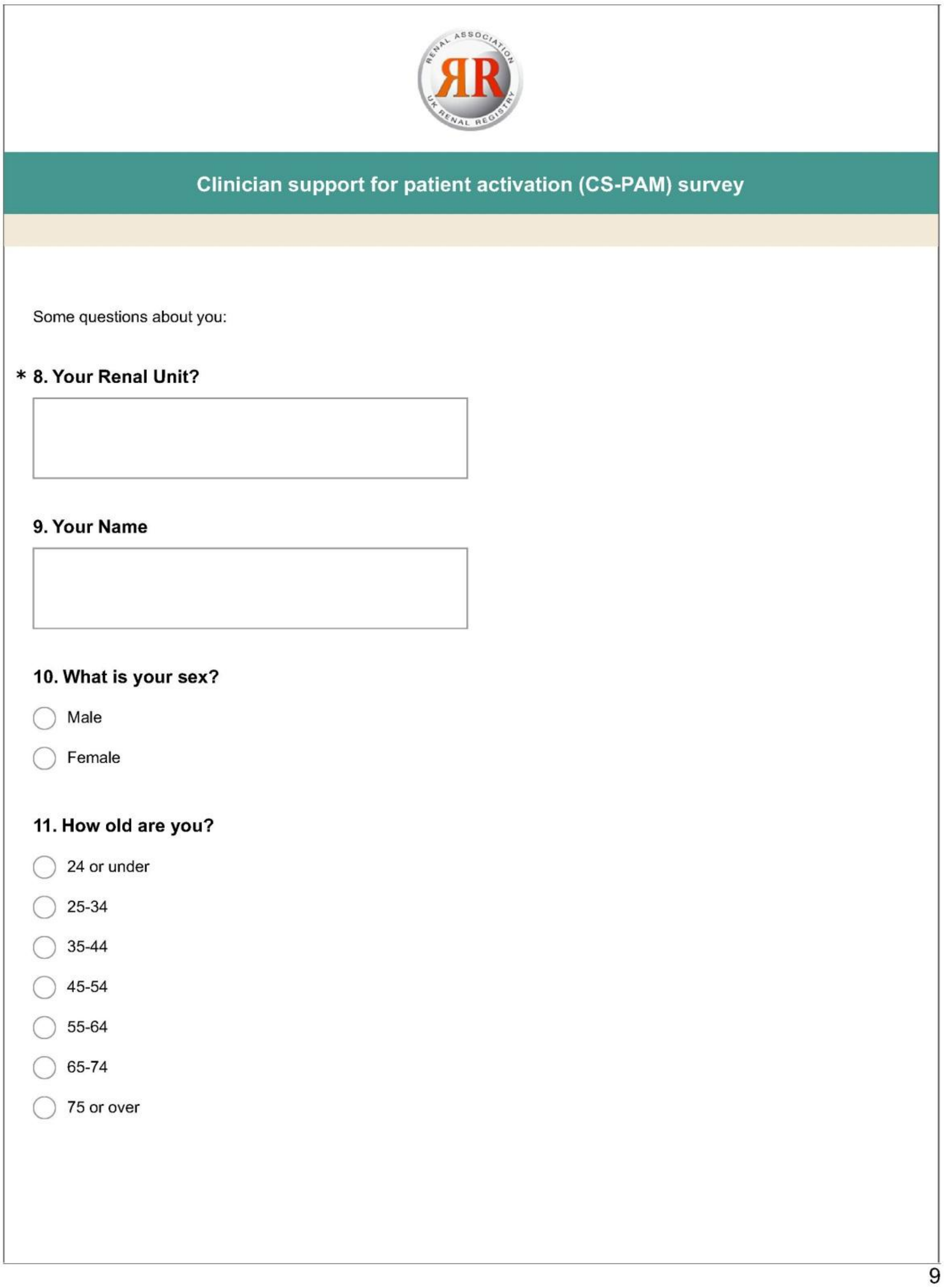


## Clinician support for patient activation (CS-PAM) survey

**7. In the last six months, when treating people with long term conditions, how often did you:**

| | Always | Mostly | Sometimes | Never | Not applicable |
|---|---|---|---|---|---|
| Ask them what change they wanted to focus on? | ○ | ○ | ○ | ○ | ○ |
| Commend them when they made even small behavioural improvements? | ○ | ○ | ○ | ○ | ○ |

Please share your thoughts about your responses here:



## Clinician support for patient activation (CS-PAM) survey

Some questions about you:

*** 8. Your Renal Unit?**

**9. Your Name**

**10. What is your sex?**

○ Male

○ Female

**11. How old are you?**

○ 24 or under

○ 25-34

○ 35-44

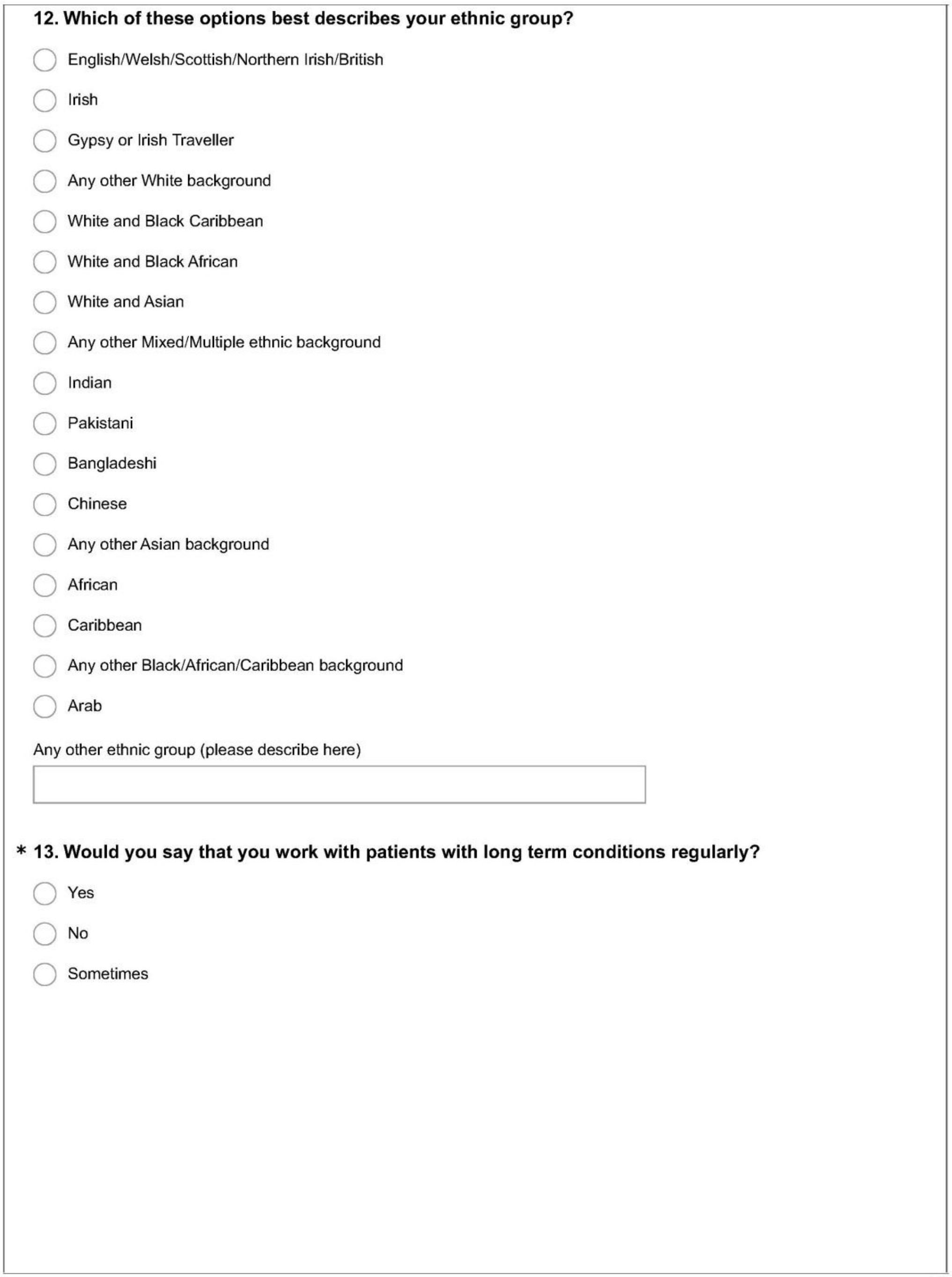
○ 45-54

○ 55-64

○ 65-74

○ 75 or over

9



**12. Which of these options best describes your ethnic group?**

○ English/Welsh/Scottish/Northern Irish/British

○ Irish

○ Gypsy or Irish Traveller

○ Any other White background

○ White and Black Caribbean

○ White and Black African

○ White and Asian

○ Any other Mixed/Multiple ethnic background

○ Indian

○ Pakistani

○ Bangladeshi

○ Chinese

○ Any other Asian background

○ African

○ Caribbean

○ Any other Black/African/Caribbean background

○ Arab

Any other ethnic group (please describe here)

* **13. Would you say that you work with patients with long term conditions regularly?**

○ Yes

○ No

○ Sometimes

10

*** 14. Which of the following best describes you?**

○ Doctor

○ Nurse

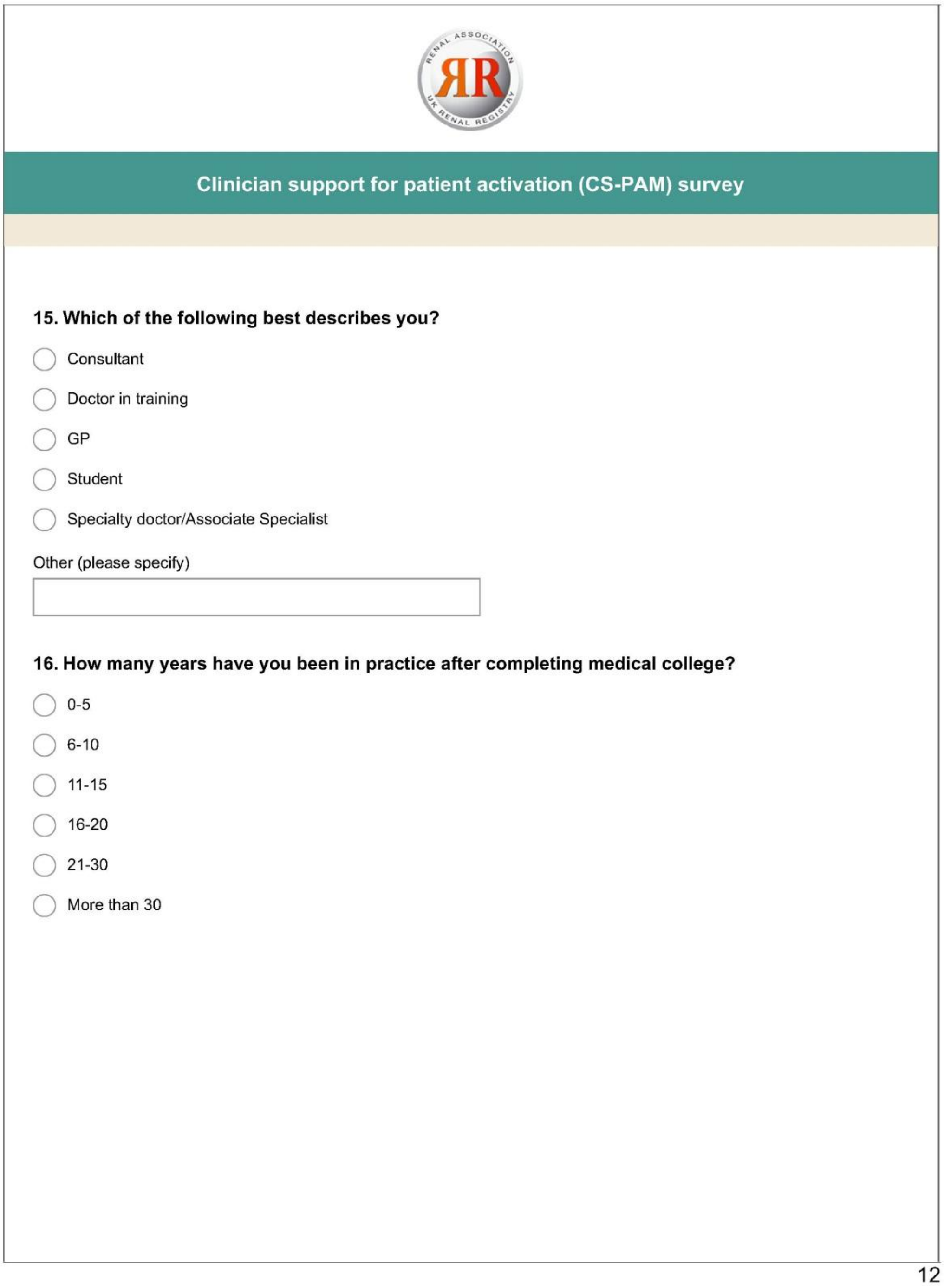
○ Allied Health Professional

○ Other

Other (please specify)

☐

11



Clinician support for patient activation (CS-PAM) survey

**15. Which of the following best describes you?**

○ Consultant

○ Doctor in training

○ GP

○ Student

○ Specialty doctor/Associate Specialist

Other (please specify)

☐

**16. How many years have you been in practice after completing medical college?**

○ 0-5

○ 6-10

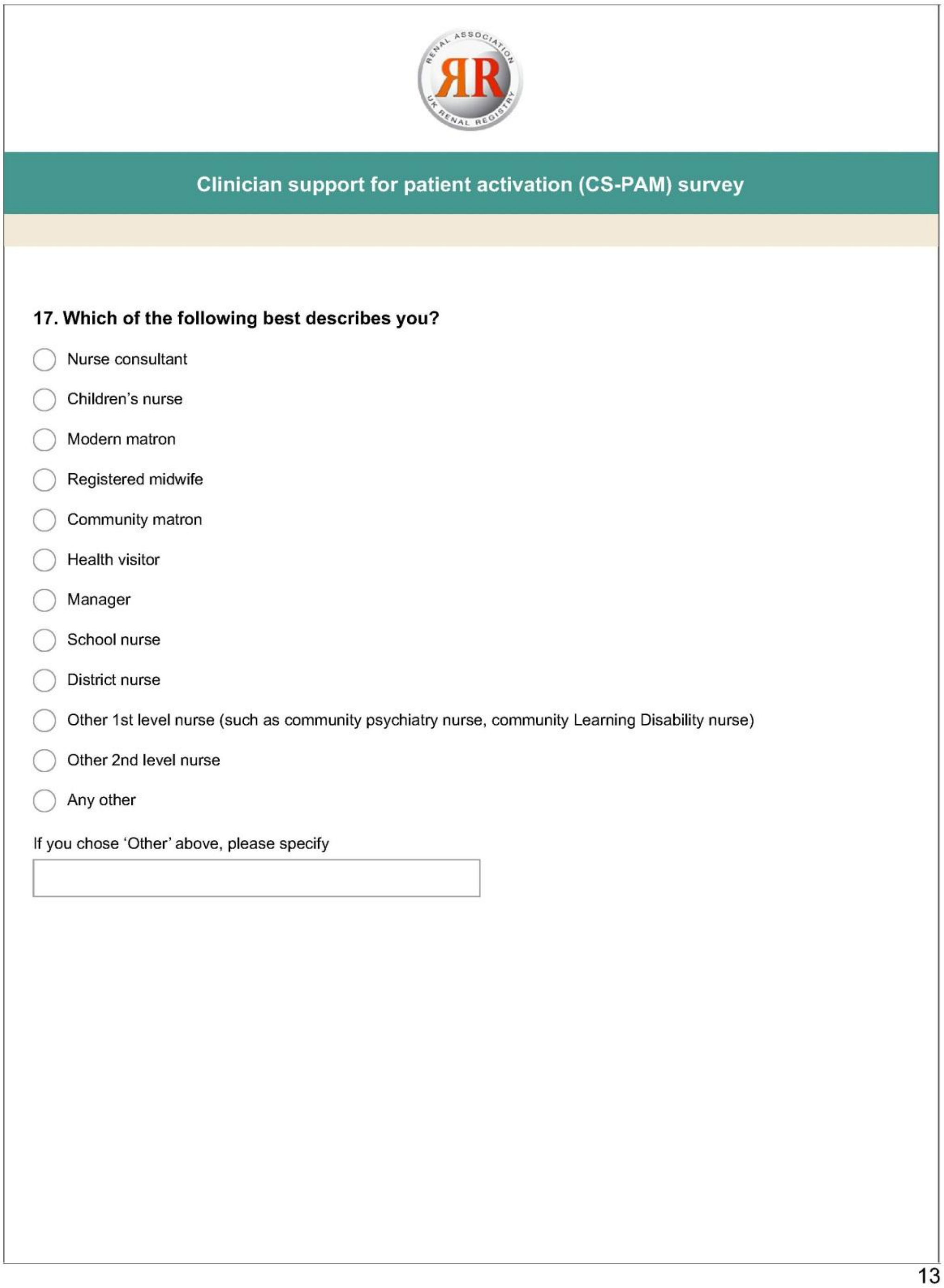
○ 11-15

○ 16-20

○ 21-30

○ More than 30

12



Clinician support for patient activation (CS-PAM) survey

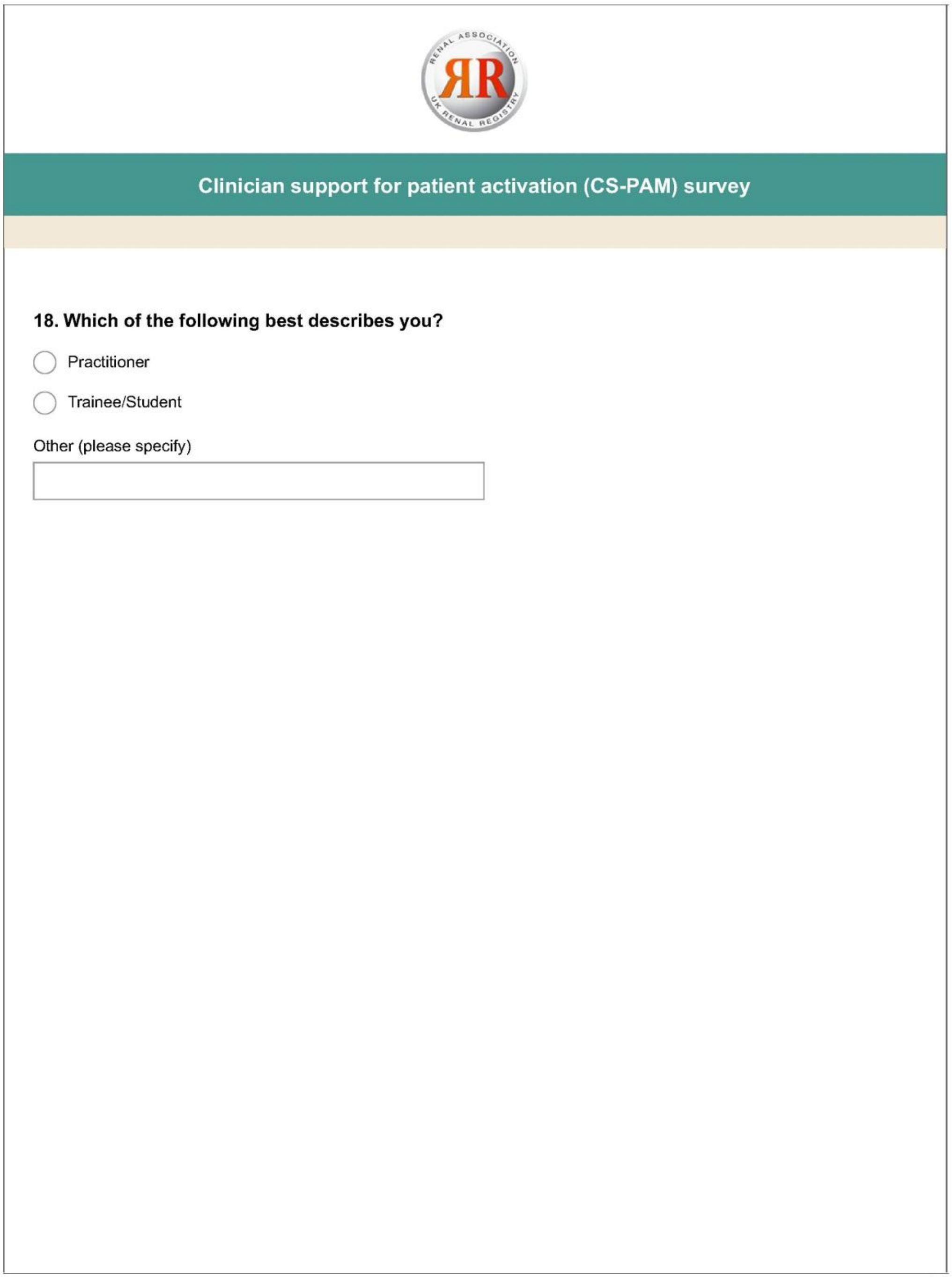
**17. Which of the following best describes you?**

○ Nurse consultant
○ Children's nurse
○ Modern matron
○ Registered midwife
○ Community matron
○ Health visitor
○ Manager
○ School nurse
○ District nurse
○ Other 1st level nurse (such as community psychiatry nurse, community Learning Disability nurse)
○ Other 2nd level nurse
○ Any other

If you chose 'Other' above, please specify

☐

13



Clinician support for patient activation (CS-PAM) survey

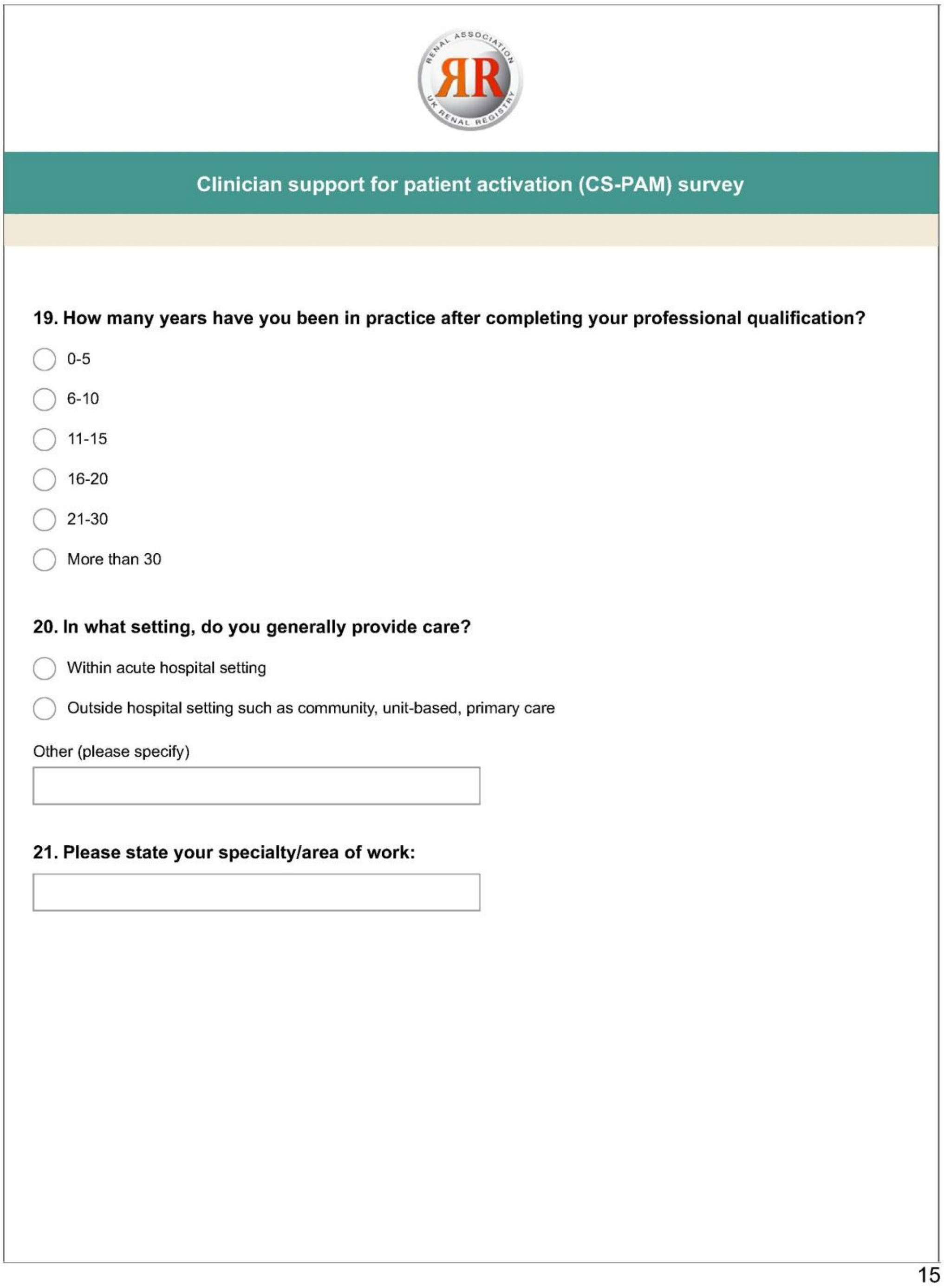
**18. Which of the following best describes you?**

○ Practitioner

○ Trainee/Student

Other (please specify)

☐



## Clinician support for patient activation (CS-PAM) survey

**19. How many years have you been in practice after completing your professional qualification?**

○ 0-5
○ 6-10
○ 11-15
○ 16-20
○ 21-30
○ More than 30

**20. In what setting, do you generally provide care?**

○ Within acute hospital setting
○ Outside hospital setting such as community, unit-based, primary care

Other (please specify)

**21. Please state your specialty/area of work:**