# The development and psychometric testing of three instruments that measure person-centred caring as three concepts - personalisation, participation and responsiveness

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RESEARCH METHODOLOGY:
INSTRUMENT DEVELOPMENT

# The development and psychometric testing of three instruments that measure person-centred caring as three concepts – Personalization, participation and responsiveness

Heather Strachan[1] | Laura Williamson[2] | Andrew Elders[3] | Ben Sutherland[4] |
Carina Hibberd[5] | Brian Williams[6]

[1]Nursing, Midwifery and Allied Health Professions Research Unit, University of Stirling, Stirling, UK

[2]Centre for Bioethics and Health Policy, Augusta University, Augusta, GA, USA

[3]Nursing, Midwifery and Allied Health Professions Research Unit, Glasgow Caledonian University, Glasgow, UK

[4]NHS Fife, Kirkcaldy, Fife, UK

[5]Faculty of Health Sciences and Sport, University of Stirling, Stirling, UK

[6]School of Nursing, Midwifery & Social Care, Edinburgh Napier University, Edinburgh, UK

**Correspondence**
Dr Heather Strachan, Research Fellow, University of Stirling, Stirling, UK.
Email: heather.strachan@stir.ac.uk

## Abstract

**Aim:** To develop and test the psychometric properties of three instruments that measure Person-centred Caring: as Personalization, Participation and Responsiveness.

**Design:** A three-phase mixed methods design used two frameworks: content validity determination and quantification; consensus-based standards for selection of health measurement instruments.

**Methods:** A narrative literature review identified the domain definition. A systematic review of instruments provided the basis for item pools, which were refined by focus groups (N = 4) of multidisciplinary staff and service users (N = 25) and cognitive interviews (N = 11) with service users. Scale content validity indexes were calculated. Three cross-sectional surveys were conducted between April 2015 and June 2016. The instruments' psychometric properties tested included factor structure, internal consistency and construct validity. Convergent validity was tested, hypothesizing that: Personalization related to relational empathy; Participation related to empowerment; and Responsiveness related to trust.

**Results:** Scale content validity indexes were ≥0.96 in all instruments. Response rates were 24% (N = 191), 15% (N = 108) and 19% (N = 124). Two factors were revealed for the Personalization and Responsiveness instruments and one factor for the Participation instrument. All had acceptable: reliability (Cronbach's Alpha >0.7); construct validity (>50%); and convergent validity (Spearman's correlation coefficient >0.25, $p < 0.05$).

**Conclusion:** This study composed definitions and instruments that reflect the multidisciplinary teams' caring behaviours, which have acceptable reliability and validity in the community population. Further psychometric testing of Participation and Responsiveness instruments should be undertaken with a larger sample.

**Impact:** The instruments can be used to monitor the variability of multidisciplinary teams' caring behaviours; research effective interventions to improve caring behaviours; and increase understanding of the impact of caring on health outcomes.

## 1 | INTRODUCTION

Caring is valued for human, professional and organizational reasons as an ethical and quality dimension of health care. Evidence indicates the importance of caring for patients to: reduce anxiety; enhance self-care ability; aid effective coping with illness; improve patient experience (Boykin, Schoenhofer, Smith, St Jean, & Aleman, 2003; Calong Calong & Soriano, 2018; Finfgeld-Connett, 2008; Larrabee et al., 2004; Palese et al., 2011; Pollack-Latham, 1996; Swanson, 1999; Tonges, McCann, & Strickler, 2014; Yeakel, Maljanian, Bohannon, & Coulombe, 2003; Zane Robinson, 2012).

Despite its value, patients' experiences of caring in health care are variable with potentially serious consequences. In the United Kingdom, independent public enquiries into serious hospital failings found a lack of compassion and uncaring attitudes among staff (Frances, 2013; MacLean, 2014). Uncaring attitudes have resulted in patients feeling: uneasy, frightened, discouraged, alienated, belittled, humiliated and vulnerable (Halldorsdottir & Hamrin, 1997; Reinman, 1986; Swanson, 1999; Wiman & Wikbald, 2004). Additionally, caring has traditionally been viewed as a nursing concept, yet patient stories suggest they value caring from all professions (Patient Opinion, n.d.).

To address this variability requires a definition and an instrument to measure caring that is relevant to the multidisciplinary team. This article describes the development and testing of three instruments to measure a new multidisciplinary definition of Person-centred Caring as three concepts: Personalization, Participation and Responsiveness.

## 2 | BACKGROUND

### 2.1 | Defining caring

Caring has been depicted as an ethic, a process, attitudes, behaviours, a relationship, a person characteristic and a consequence (Brilowski & Wendler, 2005; Finfgeld-Connett, 2008; Halldorsdottir, 2008; McCance, 2003; Morse, Bottorff, Neander, & Solberg, 1991; Swanson, 1999). Each dimension warrants a different definition and therefore instrument. A narrative review of the literature was undertaken to identify a definition suitable for a measure of multidisciplinary caring (Strachan, 2016). As no universally

**Summary**

Caring is an ethical and quality dimension valued by patients from all members of the multidisciplinary healthcare team, yet their experiences of caring can be variable. This mixed methods study developed three instruments based on a new multidisciplinary definition of caring as three concepts, Personalization, Participation and Responsiveness, to aid monitoring and improvement and help address this variability. The definition relates to the multidisciplinary teams interpersonal behaviours that reflect the ethics-of-care that aim to meet the person's health and care needs whilst 'feeling cared for'. The instruments demonstrated acceptable reliability and validity in the community population.

agreed definition of caring exists, choosing one over another was problematic. Despite many endeavours to analyse caring, authors rarely provide a definition (Buchanan & Ross, 1995; Dalpezzo, 2009; Finfgeld-Connett, 2008; McCance, McKennan, & Boore, 1997; Morse et al., 1991; Pollack-Latham, 1991; Ranheim, Karner, & Bertero, 2012; Sherwood, 1997; Smith, 1999; Sumner, 2006; Swanson, 1999; Wagner & Bear, 2009; Wilde, 1997). A review of concept analysis of caring led Sargent (2012) to suggest that finding a definition of caring was elusive. These endeavours have also been criticized for producing endless lists of attributes grouped together arbitrarily (Paley, 2001).

Furthermore, these analyses were in the nursing domain and tended to reflect everything nurses do. Conversely, there was a view that 'nursing care' is not the same as 'nurse caring' (Swanson, 1999). Nursing care reflects fundamentals of care and technical competencies, whereas nurse caring focuses on interpersonal behaviours that reflect the way care needs are met. If we defined caring as both 'what' nurses do and 'how' they do this, then by default caring becomes central to nursing. This becomes a circular debate and may mean we are debating nursing not caring.

Embracing multidisciplinary caring means disentangling 'what' from 'how' healthcare needs are met, in recognition that different professions perform diverse technical competencies and fundamentals of care, whilst interpersonal behaviours are universal. Examining uncaring behaviours provides further justification.

Uncaring was not described as ill-performed technical procedures or fundamentals of care but related to negative interpersonal behaviours such as: disinterest, insensitivity, coldness, not responding, being in a hurry, being rough and belittling (Reinman, 1986; Wiman & Wikbald, 2004).

The caring dimension chosen for this study's definition was 'interpersonal behaviours', given they are observable they are also potentially measureable. Ultimately, answering the question 'what are caring behaviours?' would be easier than solving the enigma, 'what is caring?' Given the lack of multidisciplinary definitions of caring, it was decided to create a definition based on commonality of existing caring theories attributable to multidisciplinary teams.

A framework was necessary to avoid simply creating an arbitrary list of interpersonal multidisciplinary caring behaviours. A solution was influenced by Tronto (1993) who suggests that the value of caring may be lessened if it is not contextualized as a systematic process of meeting a person's care needs. Guiding nursing practice using a systematic process to meet a person's healthcare needs is not a new idea and is called the 'nursing process'. However, the terms that describe this process (assessment, diagnosis, planning, implementation and evaluation) have been criticized for lacking a humanistic underpinning, reflecting instead a task-orientated approach to health care (Turkel, Ray, & Kornblatt, 2012). Therefore, new terms were conceived: Personalization (assessing and diagnosing a patient's health and care needs); Participation (goal setting and care planning in partnership with the patient); and Responsiveness (implementing and evaluating the plan). These terms were believed to embrace the caring process as a systematic decision-making process that values interpersonal relationships between people and the healthcare team as seeing and responding to needs emphasized by the ethics-of-care (Held, 2006; Tronto, 1993). A nominal definition was created:

> Those interpersonal behaviours of the healthcare team that support meaningful communication with the person, their family, or those close to them. Those behaviours reflect the ethics-of-care that underpin the caring processes of Personalization, Participation and Responsiveness (PPR), which are aimed at meeting the person's health and care needs whilst 'feeling cared for'.

To operationalize the nominal definition and reflect the common understanding of caring, a synthesis of ten frequently cited caring theories was undertaken. Seven theories focused on nursing (Eriksson, 1994; Halldorsdottir, 2008; McCance, 2003; Ray, 1987, 1989; Roach, 1987; Watson, 1988, 2010), one was multidisciplinary (Swanson, 1991) and two were non-health specific (Mayeroff, 1971; Tronto, 1998). The attributes of these theories that related to interpersonal behaviours relevant to the multidisciplinary team ($N = 62$) were mapped to a PPR concept. Only a few ($N = 9$) could not be mapped as they reflected either moral intent, fundamentals of care or personal characteristics rather than behaviours. The results of this mapping were reviewed to create the PPR operational definitions (see Supplementary File 1 for caring theories attributes and resulting PPR definitions).

Once caring was defined it was important to reflect on its uniqueness or otherwise. Caring has been associated with the construct of Person-centred Care (PCC), claiming similar attributes (McCance, Slater, & McCormack, 2008). Like caring, PCC has no agreed definition (Collins, 2014; Kitson, Marshall, Bassett, & Zeitz, 2013). The differences may relate to professional and ethical foundations. Caring, associated with the nursing profession (Kitson et al., 2013), has been influenced by the ethics-of-care that reflects relationships, seeing and responding to needs, and the nature of dependency and the influence of emotions on people's care needs (Gilligan, 1982; Held, 2006; Tronto, 1993). Moreover, PCC has been associated with medicine (Kitson et al., 2013) for which the generally accepted version of medical ethics by Beauchamp and Childress (2001) privileges choice, autonomy and rationality (Williamson, 2014). The disparity between these two ethical perspectives was highlighted by Mol (2008) who suggested the 'logic of choice' starts from what people want or know, whereas the 'logic of care' starts from what people need. Enabling choice is a legitimate goal of caring, likewise PCC should recognize that patients do not always have a choice, are vulnerable and may shift between active and dependent. Combining these ethical perspectives may better reflect the multidisciplinary nature of caring. Recognizing this overlap between caring and PCC, the concepts of PPR were collectively grouped into the construct of Person-centred Caring (PCCg) (Strachan, 2016).

## 2.2 | Instruments that measure Person-centred Caring

Before developing a new instrument, it is imperative to identify if one already exists. A systematic review of instrument development studies that measured caring, PPR and related concepts was undertaken (Strachan, 2016). However, it proved difficult to relate these instruments to PPR definitions due to the frequent lack of conceptual clarity. Of the 122 studies reviewed in full, only 15% ($N = 18$) reported a definition of what the instrument intended to measure; 25% ($N = 30$) reported a theoretical or conceptual basis for their instrument. Many instruments' items were a mixture of attitudes, beliefs and behaviours, which may measure different things (Choi & Pak, 2005; de Vaus, 2014).

Some instruments were associated with PPR concepts but not adequately. Instruments that measured relational empathy ($N = 2$) reflected Personalization but included items relevant to Participation and Responsiveness. Instruments that measured shared decision-making ($N = 6$) related to Participation but focused on single event decision-making rather than different levels of patients' involvement in their health care.

The decision was taken to develop three new instruments. The authors believed that each PPR concept was itself a principal concept. The instruments could be used independently as each

concept would likely require different improvement approaches. Finally, three shorter instruments would not overburden survey respondents. A postal patient-reported survey instrument was the data collection method chosen. This reflected the instruments': purpose, topic area, population and evidence of advantages and disadvantages of the range of data collection methods (de Vaus, 2014; McColl et al., 2001). The instruments would be tested in the community setting, as the authors found few instruments relevant to this setting.

## 3 | THE STUDY

### 3.1 | Aim

To develop and test the psychometric properties of three instruments that measure Person-centred Caring: as Personalization, Participation and Responsiveness.

### 3.2 | Methodology

A three-phase mixed methods design was used (Figure 1) based on classical test theory (Streiner & Norman, 2008). Phase one and two were guided by Lynn's (1986) content validity determination and quantification method. Terwee et al.'s (2007) consensus-based standards for selection of health measurement instruments (COSMIN) guided phase three.

### 3.3 | Phase one instrument development

This phase involved domain identification and item generation (Lynn, 1986). The PPR definitions identified from the narrative review provided the domains for which the instruments would be developed to measure. The sources for initial item generation were the 122 instrument studies identified during the systematic review (Strachan, 2016). One researcher reviewed and coded instrument items ($N = 2,834$) that related to interpersonal behaviours of multidisciplinary staff and had face validity to the PPR concepts ($N = 881$). Table 1 provides the coding structure. Duplicate items were removed. A second researcher checked these, and discrepancies were resolved by agreement. This resulted in item pools for the Personalization instrument ($N = 22$), Participation instrument ($N = 28$) and Responsiveness instrument ($N = 24$).

The instrument response option chosen was frequency, based on the assumption that staff should perform behaviours represented by the items at all times. The survey instructions asked patients to think about any health care they received in the last month and to make an assessment of how frequently the behaviours listed happened. The response option verbal labels were: 'never', 'almost never', 'sometimes', 'almost always' and 'always'. This wording was distinctive, understandable and provided the complete possible range. To prevent



**Phase 1**

**Instrument Development**

Domain Identification
A narrative literature review supported the identification of the concepts of Personalization, Participation & Responsiveness (P,P&R)

Item Generation
A mixed methods systematic review supported the generation of 3 item pools for 3 new instruments to measure P,P&R

**Phase 2**

**Instrument Refinement**

Instrument Formation
Focus groups to assimilate items from pool into a usable format to support face and content validity. Cognitive Interviews to reduce response bias.

Judgment Quantification
Survey with staff and service user representatives to identify Item content validity index and scale content validity index.

**Phase 3**

**Instrument Testing**

Cross Sectional Observation Survey
Pilot and distribution of 3 new instruments to sample of population.

Psychometric Testing
Analyse responses to ascertain validity, reliability, responsiveness, feasibility and acceptability of the 3 new instruments in the sample population.
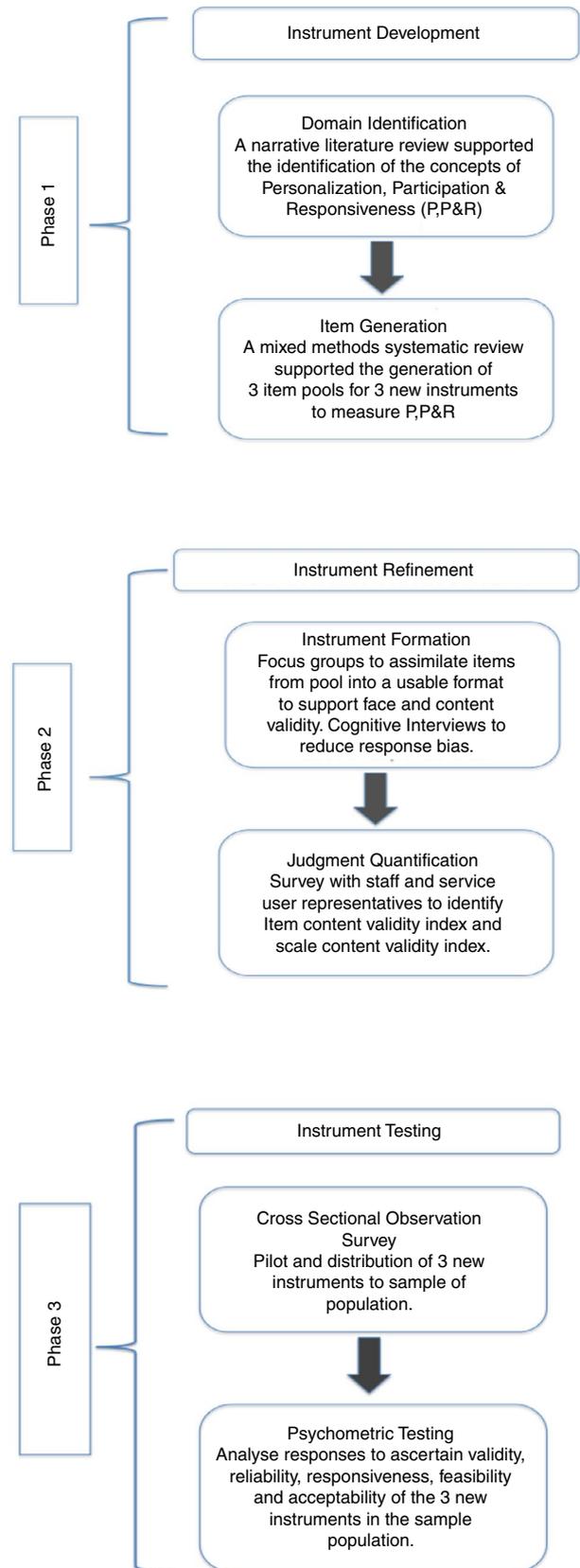
**FIGURE 1** Study design phases

spurious representativeness, a 'does not apply' (DNA) response option was added. Some items were reworded to ensure consistency with the response option.

**TABLE 1** Coding structure for multidisciplinary caring behaviours derived from items of 122 instruments reviewed that measure caring, personalization, participation, responsiveness, person-centred care and related concepts

| PERSONALIZATION | | |
|---|---|---|
| Connecting | Knowing | Empathizing |
| 1. Non-verbal cues<br>2. Courteous & friendly<br>3. Introductions made<br>4. Social conversation | 1. Prior knowledge<br>2. Listened actively<br>3. Encourage conversation<br>4. Explores emotions<br>5. Explores concerns<br>6. Explores health issues<br>7. Explores lifestyle issues<br>8. Explores values/beliefs/<br>priorities | 1. Acknowledges<br>understanding |
| **PARTICIPATION** | | |
| Involving | Goals Setting | Shared Decision-Making |
| 1. Encouraged questions<br>2. Family involvement<br>3. Giving information<br>4. Informed about condition<br>5. Informed about treatment<br>6. Informed about tests<br>7. Enabled in care<br>8. Consulted about care<br>9. Understandable<br>explanations | 1. Goals discussed<br>2. Health outcomes discussed<br>3. Positive but realistic views<br>4. Explored ideas and<br>expectations | 1. Preference re involvement<br>2. Discuss options/information<br>3. Benefits & risks<br>4. Uncertainties & concerns<br>5. Roles, responsibilities,<br>resources<br>6. Mutually agree decision<br>7. Flexible and personal<br>8. Summaries understanding |
| **RESPONSIVENESS** | | |
| Attentiveness | Anticipating | Reciprocity |
| 1. Being with or available<br>2. Respond to concerns/<br>requests<br>3. Willing and helpful<br>4. Timing of care<br>5. Checking or monitoring<br>6. Privacy | 1. Teamwork and sharing<br>information<br>2. Future care needs<br>3. Possible problems &<br>response<br>4. Informed about what to<br>expect<br>5. Informed what to watch for | 1. Reinforce & encourage<br>2. Information on results<br>3. Feedback and progress<br>4. Review improvements,<br>needs or concerns<br>5. Continue, adapt or cease<br>care plan |

## 3.4 | Phase two instrument refinement

This incorporated instrument formation with focus groups and cognitive interviews. Additionally, judgement quantification involved a survey to identify the instruments' content validity index (CVI). Both service user representatives and multidisciplinary staff were involved, as it was believed they all had a contribution to make to identify appropriate, realistic and desirable caring behaviours.

A convenience sample of NHS staff ($N = 80$) and service user representatives ($N = 15$) were invited to participate in a focus group by email or letter. Those who responded were sent a participant information sheet, consent form and focus group dates. Their task was to review the three PPR item pools for relevance, comprehensiveness and comprehensibility to the PPR definitions and study population.

Three focus groups were held with staff ($N = 19$) from one Health Board in Scotland including: occupational therapists ($N = 5$), specialist nurses ($N = 4$), physiotherapists ($N = 3$), community nurses ($N = 2$), psychologists ($N = 2$), a dietician ($N = 1$), a medical consultant ($N = 1$) and a care manager ($N = 1$). Sixteen were female and three

were male. One focus group involved service user representatives from the Neurological Alliance of Scotland (NAS) and included male ($N = 2$) and female ($N = 4$) representatives.

Focus groups were recorded and transcribed verbatim. Two researchers independently reviewed the transcripts to discover patterns across focus groups' comments and then discussed their findings. This resulted in: 26 items with no changes, 26 items reworded, 22 items removed and the addition of five new items. A reduction from 74–57 items (Personalization instrument × 16, Participation instrument × 22, Responsiveness instrument × 19).

A different convenience sample of service user representatives from NAS ($N = 20$) were invited to participate in cognitive interviews to ascertain whether the instruments' items would generate the intended information. A concurrent, verbal probing technique was used to examine: comprehension of the instruments' items, decisional and response processes (Beatty & Willis, 2007). Interviews were conducted for the Personalization ($N = 4$), Participation ($N = 3$) and Responsiveness ($N = 4$) instruments, with male ($N = 4$) and female ($N = 7$) participants. Interviews (43–94 min) were transcribed verbatim. Two researchers independently summarized the interview data. Patterns across participants' responses and

discoveries from a few participants were discussed. Further interviews (N = 4) were conducted to review the 13 additional or significantly reworded items across all instruments. Two researchers independently reviewed the data from each interview. This resulted in: three items removed, three additional items and six items spilt into two items, an increase from 57–63 items (Personalization instrument × 20, Participation instrument × 24, Responsiveness instrument × 19).

Judgement quantification (Lynn, 1986) involved sending an email survey to staff (N = 19) and service users (N = 6), who previously attended the focus groups, to identify the instruments' item and scale CVI. Participants were asked to rate each item for relevance to the PPR definitions using a four-point ordinal rating scale: 'not relevant', 'relevance unclear', 'relevant with minor alterations', 'relevant without alterations'.

## 3.5 | Phase three instrument testing

Instrument testing involved three cross-sectional surveys with different samples of patients from community/outpatient settings. The instruments were piloted. Whilst these resulted in no changes to the instruments themselves, a question asking patients about the 'professionals included in their healthcare team' was given additional response choices to better reflect possible options.

## 3.6 | Sample, participants and data collection

A non-probability convenience sample was used to recruit patients from two Scottish Health Boards. A sample size of five cases per item has been suggested for factor analysis (DeVon et al., 2007). Anticipating a response rate of 20%, based on similar surveys conducted in primary care (Scottish Government, 2014), required 600 surveys sent to eligible patients. These included adults (age ≥18 years) receiving health care currently or recently discharged from community/outpatient healthcare services. Exclusion criteria for the survey were patients who: the healthcare team believed could be harmed if they were involved; lived in nursing homes; lacked cognitive ability to consent to participate; or were not sufficiently fluent in English to understand the questions.

Each instrument was sent to a different sample of patients (Personalization N = 796, Participation N = 705, Responsiveness N = 644) between April 2015 - June 2016. Community nursing staff identified patients from their case list who met the inclusion criteria and administration staff posted survey packs containing a covering letter, the survey and a prepaid reply envelope. Community/outpatient rehabilitation patients from one Health Board, were issued survey packs by reception staff at an outpatient visit or posted on discharge, whichever was sooner.

Data collection additionally involved distributing an instrument that measured a related concept to assess convergent validity. The authors' permission to use their instruments was obtained.

The Personalization instrument was distributed with the Consultation and Relational Empathy© (CARE©) Measure, a measure of relational empathy (Mercer, Maxwell, Heaney, & Watt, 2004). The definition of Personalization included empathy and was therefore considered a related concept. Empathy is an accepted attribute of a caring relationship (Finfgeld-Connett, 2008; Halldorsdottir, 2008).

The Participation instrument was distributed with the Healthcare Empowerment Questionnaire© (HCEQ©), a measure of empowerment (Gagnon, Hébert, Dubé, & Dubois, 2006). Castro, Van Regenmortel, Vanhaaecht, Sermeus, and Van Hecke (2016) suggest that without patient participation in their health care, it is impossible to promote patient empowerment.

The Responsiveness instrument was distributed with the Healthcare Relationship (HCR) Trust Scale© , a measure of trust between the healthcare team and patients (Bova, Fennie, Watrous, Dieckhaus, & Williams, 2006; Bova et al., 2012). The definition of Responsiveness included reciprocity, which is viewed as a central feature of patient trust (Bova et al., 2012).

Data related to patients' characteristics and their health care were collected to explore the effect of demographics and clinical variables on the instruments. No follow-up reminders were issued to assure respondents of complete confidentiality and anonymity.

## 3.7 | Data analysis

Analysis of CVI was based on Lynn's (1986) method. The proportion of experts, whose positive endorsement was required to establish item content validity beyond the 0.05 significance level was identified using an extended significance combination table. Each items' CVI (I-CVI) was calculated and combined to ascertain each instruments' scale CVI (S-CVI). The recommended criterion for S-CVI acceptability is >0.90 (Polit & Beck, 2006).

Returned survey data were entered onto a spreadsheet and transferred onto IBM SPSS V 22.0 for analysis (IBM IBM Corp, 2013). A statistical analysis plan was developed a priori based on the COSMIN checklist (Terwee et al., 2007).

Descriptive statistics were used to present characteristics of respondents and their health care. Inferential statistics tested normality distributions of variables (Shapiro–Wilk tests), sample-selection bias for age (Wilcoxon signed-rank tests), non-response bias for age (One Sample Wilcoxon signed-rank tests) and non-response bias for gender (chi-squared goodness of fit tests). Prior to factor analysis, problematic items were removed based on items with: more than 20% missing or 'DNA' responses; high skewness and high kurtosis.

Complete case Exploratory Factor Analysis (EFA) was undertaken following verification of the sampling adequacy using a Kaiser–Meyer–Olkin (KMO) test for which values above 0.8 are considered 'great' (Field, 2012). Higher values of the KMO statistic indicates greater adequacy for EFA based on the partial correlation structure (common variance) between variables and hence a better ability for one variable to be predicted by other variables.

Bartlett's test of sphericity indicated whether correlation between items was sufficiently large for EFA, for which $p < 0.05$ is considered significant (Williams, Brown, & Onsman, 2010). Factor rotation used oblique rotation (oblimin) because conceptually the items and factors were highly likely to be correlated. Initial EFA informed the elimination of items that loaded on more than one factor or eigenvalues <0.5. Factor analysis was repeated, and factor extraction was considered using multiple criteria including: scree plots, eigenvalues over Kaiser's criterion of >1 and conceptual applicability (Field, 2012).

Each factor identified was assessed for evidence of internal consistency. A Cronbach's alpha of ≥0.7 was considered appropriate (Terwee et al., 2007). Construct validity was supported if items loaded onto factors that explain at least 50% of the variance (Terwee et al., 2007).

Convergent validity examined the correlation (Spearman's correlation coefficient) between respondents' PPR instrument scores and instruments of a theoretically related concept. These instruments underwent complete case EFA to assess their reliability and validity in this population.

Prior to assessing for convergent validity, cases with more than 20% missing or DNA responses were removed from the analysis. Personal mean score imputation was applied to remaining missing or DNA responses in each case. Scores were calculated for each PPR instrument ('Never' = 0, 'Almost never' = 1, 'Sometimes' = 2, 'Almost always' = 3, 'Always' = 4) and tested for normality. Convergent validity was supported if the PPR and related concept instruments' scores correlated moderately (between 0.25-0.5; Terwee et al., 2007).

Instrument acceptability and feasibility were explored by seeking evidence of an association (Spearman's correlation coefficient) between 'ease of completing the survey', 'the number of healthcare professionals attending' and 'number of visits'. It was hypothesized that patients might find it more difficult to complete the survey the greater the number of health professions or visits they had to consider.

The ability of the instruments to detect differences between groups of patients that are known, or suspected, to influence the instrument scores was examined (Kruskal–Wallis tests). The groups were defined by age and health status, which have been found to influence patient satisfaction with healthcare quality (Crow et al., 2002). In addition, gender and healthcare teams were examined. Frequency distributions were examined to provide evidence of ceiling effects (>15% cases with the highest scores) and floor effects (<15% cases with the lowest scores; Terwee et al., 2007).

Ethics committee approval was obtained from the NHS East of Scotland Research Ethics Service (IRAS Study ID 160971). Written consent was obtained from focus group and interview participants. Consent was assumed on return of the survey forms to the researcher. Transcripts were de-identified and other identifiable information was kept secure and destroyed at the end of the study.

# 4 | RESULTS

## 4.1 | Results of judgement quantification survey

The responses to the judgement quantification survey ($N = 15$) included: service user representatives ($N = 3$) and staff ($N = 12$). Thirteen were included in the analysis (two were completed incorrectly) comprising male ($N = 2$) and female ($N = 11$) participants. Results revealed near perfect agreement from all participants, meaning content validity were supported for all three instruments (Personalization instrument S-CVI = 0.99, Participation instrument S-CVI = 0.99, Responsiveness instrument S-CVI = 0.96).

## 4.2 | Results of instrument testing

The response rate of the Personalization instrument was 24% ($N = 191$). One survey was spoilt, therefore discounted. Thirteen cases from the pilot were added ($N = 203$). The response rate for the Participation instrument was 15% ($N = 108$). Six cases from the pilot were added ($N = 114$). The response rate for the Responsiveness instrument was 19% ($N = 124$). Twelve cases from the pilot were added ($N = 136$). Tables 2 and 3 provide characteristics of respondents' and their health care.

There was weak evidence of an age sample-selection bias ($p = 0.045$) and age non-response bias ($p = 0.001$) for the Personalization instrument. There was no evidence of age sample-selection bias or age non-response bias for the Participation instrument. There was weak evidence of age sample-selection bias ($p = 0.049$) and age non-response bias ($p = 0.002$) for the Responsiveness instrument. Older service users were less likely to receive or respond to the survey. There was no evidence ($p \geq 0.05$) that respondents' gender differed from the population or the sample for all three instruments.

Complete Case ($N = 154$) EFA revealed the Personalization instrument had two factors (factor 1 'Connecting', factor 2 'Knowing'). The Kaiser–Meyer–Olkin measure verified the sampling adequacy for the analysis (KMO = 0.89). Bartlett's test of sphericity, $p < 0.001$ indicating sufficient correlations exist for EFA. The two factors had eigenvalues >1 and in combination explained 67.73% of the variance. Each factor had evidence of internal reliability, Cronbach's $\alpha = 0.92$ (95% CI 0.90–0.94) and Cronbach's $\alpha = 0.92$ (95% CI 0.89–0.93; Table 4).

Prior to testing for convergent validity, complete case ($N = 177$) EFA was conducted on the CARE© Measure. A one factor solution was revealed with an eigenvalue >1 explaining 81.95% of the variance. There was evidence of internal reliability, Cronbach's $\alpha = 0.97$ (95% CI 0.97–0.98). These results were similar to studies that tested the instrument's psychometric properties (Bikker, Fitzpatric, Murphy, & Mercer, 2015; Mercer & Murphey, 2008). Scores of the Personalization instrument and CARE© Measure ($N = 184$) were significantly correlated ($r_s = 0.71$, $p = 0.001$).

**TABLE 2** Respondents characteristics

| | Personalization survey (N = 203) | Participation survey (N = 114) | Responsiveness survey (N = 136) |
|---|---|---|---|
| Age | Mean (years) and standard deviation | Mean (years) and standard deviation | Mean (years) and standard deviation |
| All | 68 (SD 17) | 76 (SD 14) | 70 (SD 17) |
| Male | 65 (SD 18) | 75 (SD 12) | 67 (SD 16) |
| Female | 70 (SD 16) | 76 (SD 16) | 73 (SD 17) |
| Missing | 9 | 5 | 8 |
| Gender | Frequency | Frequency | Frequency |
| Male | 76 (37%) | 42 (37%) | 61 (45%) |
| Female | 125 (62%) | 70 (62%) | 69 (51%) |
| Missing | 2 | 2 | 6 |
| Ethnicity | Frequency | Frequency | Frequency |
| White Scottish, British, Irish, Polish or other | 198 (99%) | 110 (96%) | 128 (98%) |
| Asian, Asian Scottish or British | 1 | 0 | 1 |
| Mixed or multiple ethnic group | 1 | 0 | 1 |
| African | 0 | 0 | 0 |
| Caribbean or black | 0 | 0 | 0 |
| Other | 0 | 0 | 0 |
| Missing | 3 | 4 | 6 |
| Health state | Frequency | Frequency | Frequency |
| Very good | 10 (5%) | 6 (5%) | 5 (4%) |
| Good | 42 (21%) | 30 (26%) | 39 (28%) |
| Fair | 118 (58%) | 54 (47%) | 65 (48%) |
| Bad | 25 (12%) | 16 (14%) | 22(16%) |
| Very bad | 4 (2%) | 3 (3%) | 2 (1%) |
| Missing | 4 | 5 | 3 |

Complete case (N = 47) EFA revealed the Participation instrument had one factor. The Kaiser–Meyer–Olkin measure verified the sampling adequacy for the analysis (KMO = 0.85). Bartlett's test of sphericity, $p < 0.001$ indicating sufficient correlations exist for EFA. The factor had an eigenvalue >1 which explained 58.35% of the variance. There was evidence of internal reliability, Cronbach's $\alpha$ = 0.92 (95% CI 0.89–0.95; Table 5).

Prior to testing for convergent validity, complete case (N = 93) EFA was conducted on the HCEQ©. Three factors were revealed with eigenvalues >1 and combined explained 65% of the variance. Each factor had evidence of internal reliability: Cronbach's $\alpha$ = 0.87 (95% CI 0.82–0.90), Cronbach's $\alpha$ = 0.87 (95% CI 0.81–0.91), Cronbach's $\alpha$ = 0.89 (95% CI 0.85–0.92). These results confirmed the original instrument development study, with the same items loading on each factor (Gagnon et al., 2006). Scores of the Participation instrument and HCEQ© (N = 83) were moderately correlated ($r_s$ = 0.27, $p$ = 0.011).

Complete case (N = 78) EFA revealed the Responsiveness instrument had two factors (factor 1 'Being Attentive', factor 2 'Reciprocity'). The Kaiser–Meyer–Olkin measure verified the sampling adequacy for factor analysis (KMO = 0.84). Bartlett's test of sphericity, $p < 0.001$ indicating sufficient correlations exist for EFA. The two factors had eigenvalues >1 and combined explained 71.26% of the variance. The two factors had evidence of internal reliability, Cronbach's $\alpha$ = 0.91 (95% CI 0.88–0.94) and Cronbach's $\alpha$ = 0.93 (95% CI 0.91–0.95; Table 6).

Prior to testing for convergent validity, complete case (N = 115) EFA was conducted on the HCR Trust Scale©. A one factor solution was revealed with an eigenvalue >1 and explained 61.20% of the variance. The factor had evidence of internal reliability, Cronbach's $\alpha$ = 0.94 (95% CI 0.92–0.95). These results were like the instrument validation study in the primary care setting (Bova et al., 2012). Scores of the Responsiveness instrument and HCR Trust Scale© (N = 112) were significantly correlated ($r_s$ = 0.62, $p$ = 0.001).

Based on the factor analyses all instruments' definitions were revised to ensure conceptual clarity of factors' items with the PPR concepts (Table 7).

|  | Personalization survey (N = 203) | Participation survey (N = 114) | Responsiveness survey (N = 136) |
|---|---|---|---|
| The team in attendance in the past month | Frequencies and frequency distributions | Frequencies and frequency distributions | Frequencies and frequency distribution |
| GP | 124 (61%) | 77 (68%) | 74 (54%) |
| Community nurse | 78(38%) | 56 (49%) | 74 (54%) |
| Hospital doctor | 111 (54%) | 54 (47%) | 72 (53%) |
| Hospital nurse | 90 (44%) | 48 (42%) | 61 (42%) |
| Physiotherapist | 107 (53%) | 36 (31%) | 41 (30%) |
| Occupational therapist | 76 (37%) | 21 (18%) | 37 (27%) |
| Support staff | 56 (28%) | 28 (25%) | 35 (26%) |
| Specialist nurse | 45 (22%) | 8 (7%) | 31 (23%) |
| Podiatrist | 35 (17%) | 29 (25%) | 29 (17%) |
| Dietician | 13 (6%) | 11 (10%) | 14 (10%) |
| Speech & language therapist | 4 (2%) | 0 | 9 (7%) |
| Psychology | 18 (9%) | 3 (3%) | 7 (5%) |
| Other | 21 (10%) | 15 (13%) | 20 (15%) |
| Places health care received in past month |  |  |  |
| Home | 113 (56%) | 66 (58%) | 87 (64%) |
| Clinic/outpatient | 114 (56%) | 48 (42%) | 75 (55%) |
| GP/HC | 94 (46%) | 62 (54%) | 47 (35%) |
| Inpatient | 36 (18%) | 23 (20%) | 37 (27%) |
| Day hospital | 17 (8%) | 15 (13%) | 18 (13%) |
| Other | 13 (6%) | 9 (8%) | 8 (6%) |
| Number of visits in the past month |  |  |  |
| 1–4 | 87 (43%) | 46 (40%) | 47 (35%) |
| 5–10 | 58 (29%) | 29 (25%) | 37 (27%) |
| 11 or more | 36 (18%) | 35 (32%) | 37 (27%) |
| Missing | 22 | 4 | 15 |
| Number of different professions seen |  |  |  |
| 1 | 21 (10%) | 18 (16%) | 15 (11%) |
| 2 | 29 (14%) | 13 (11%) | 20 (15%) |
| 3 | 36 (18%) | 21 (18%) | 23 (17%) |
| 4 | 42 (21%) | 21 (18%) | 19 (14%) |
| 5 | 33 (16%) | 14 (12%) | 22 (16%) |
| 6 | 16 (8%) | 7 (6%) | 15 (11%) |
| 7 | 14 (7%) | 8 (7%) | 7 (5%) |
| 8 | 7 (3%) | 1 (1%) | 5 (4%) |
| 9 | 1 (1%) | 1 (1%) | 1 (1%) |
| 10 | 0 | 1 (1%) | 0 |
| Missing | 4 | 9 | 9 |

**TABLE 3** Respondents' healthcare characteristics

Most respondents reported all three instruments were 'very easy' to complete (67%, 49%, & 64%) or 'somewhat easy' (22%, 33%, 28%). There was no evidence of a significant relationship between reported ease of completing the survey and the number of visits, for all instruments. Only the Personalization instruments had weak evidence of a relationship between ease of completing the survey and greater number of different professions seen ($r_s = 0.21$, $p = 0.002$).

There was evidence that two instruments could detect an association between age of respondents and their instrument scores: Personalization instrument ($r_s = -0.23$, $p = 0.002$) and

**TABLE 4** Summary of complete case exploratory factor analysis for the 12 item personalization instrument (n = 154)

| The people involved in my health care......... | Factor 1 | Factor 2 |
|---|---|---|
| A2...explained what they were there to do | **0.880** | 0.163 |
| A1...showed an interest in me as a person | **0.825** | −0.110 |
| A5...used appropriate body language, including facial expressions | **0.810** | 0.019 |
| A4...made eye contact and focused their attention on me | **0.802** | −0.101 |
| A1...introduced themselves on meeting me | **0.765** | 0.035 |
| A1...took enough time to understand how my health affects me | **0.647** | −0.176 |
| A3...gave me opportunities to offer information about myself | **0.644** | −0.183 |
| A9...knew relevant information about me and my health | **0.599** | −0.124 |
| A1...explored things in my life that might influence my health | −0.080 | **−0.939** |
| A1...showed an interest in my health experiences | 0.146 | **−0.818** |
| A1...showed an interest in my family, or those close to me | 0.030 | **−0.795** |
| A1...talked to me about how I felt about my health | 0.249 | **−0.667** |
| Eigenvalues | 7.592 | 1.137 |
| % of variance | 60.70% | 7.03% |
| alpha | 0.924 | 0.921 |

Factors loadings over 0.50 are shown in bold.

Responsiveness instrument ($r_s$ = −0.24, $p$ = 0.01). There was evidence that the Personalization instrument was responsive to health status ($p$ = 0.039) and different healthcare teams ($p$ = 0.008). A ceiling effect was present for all three instruments (Personalization 29%, Participation 18%, Responsiveness 39%).

## 5 | DISCUSSION

Before developing a new instrument, it is important to ascertain if one already exists, however this proved difficult, as many authors of instrument studies did not report a theoretical underpinning or definition for their instrument. Authors of systematic reviews of related topics have also reported this issue (Bowling et al., 2012; Crow et al., 2002; Dy, 2007; Herbert, Gagnon, Rennick, & O'Loughlin, 2009). It has been proposed that there are limitations to using instruments linked to a specific caring theory, as a theory may not reflect a wide range of caring practice (Piredda et al., 2017). However, if measures are not based on a definition, it is difficult to be clear what is being measured and therefore how to interpret the results.

Preliminary psychometric testing of the PPR instruments suggests that internal reliability, content validity, construct and convergent validity in this population were supported, according to the criteria identified

**TABLE 5** Summary of complete case exploratory factor analysis for the 10 item participation instrument (n = 47)

| The people involved in my health care......... | Factor 1 |
|---|---|
| A18...gave me the information I needed to make decisions that were right for me | **0.853** |
| A20...respected my right to choose the care and treatment I wanted | **0.847** |
| A9...gave me encouragement and opportunities to do what I could for myself | **0.814** |
| A15...encouraged me to be involved in decision about my health care as much as I wanted to be | **0.810** |
| A19...discussed my concerns about managing my health | **0.798** |
| A8...kept me up-to-date about my health and care as much as I wanted to be | **0.760** |
| A5...checked to make sure I understood the information I was given about my health and care | **0.698** |
| A10...discussed my expectations about how my health would be managed | **0.692** |
| A22...planned my healthcare so everyone was working towards the same goals | **0.686** |
| A1...encouraged me to ask questions about my health and care | **0.647** |
| Eigenvalues | 6.235 |
| % of Variance | 58.357% |
| alpha | 0.928 |

Factors loadings over 0.50 are shown in bold.

by Terwee et al., (2007) and recently updated (Prinsen et al., 2018). Feasibility and acceptability were also indicated. It was not possible to examine the instruments' responsiveness to change (test–retest reliability) as repeat administration to assess the same set of circumstances was not possible as people were still in receipt of health care.

When examining survey results, it is important to consider the health and demographic profile of respondents. This study found that respondents who self-reported 'bad' and 'very bad' health states had lowest Personalization instrument scores. This is consistent with other studies that report sicker patients record lower satisfaction with the quality of care (Crow et al., 2002). Results from this study indicate weak but significant negative correlation with age and scores of the Personalization and Responsiveness instrument. This result is contrary to conventional understanding in relation to empathy where younger patients perceived the general practitioner (GP) as having less empathy than older patients (Mercer, McConnachie, Maxwell, Heaney, & Watt, 2005). Likewise, Crow et al. (2002) found that older people were generally more satisfied with their care than younger people. None of the studies reviewed related to community settings.

### 5.1 | Limitations

Response rates were low, although similar to other studies in primary care (Scottish Government, 2014). Likewise, complete case factor analysis reduced the sample size below the desirable five cases

**TABLE 6** Summary of complete case exploratory factor analysis for the 12 items responsiveness instrument (*n* = 78)

| The people involved in my health care......... | Factor 1 | Factor 2 |
|---|---|---|
| A10...knew which other healthcare staff were involved in my health care | **0.895** | 0.061 |
| A1...gave me their full attention when they were with me | **0.890** | 0.084 |
| A11...gave me information and advice that was consistent from person to person | **0.883** | 0.052 |
| A8...did what they said they would do | **0.802** | −0.097 |
| A6...spent time with me to meet my healthcare needs | **0.764** | −0.115 |
| A7...were willing to be flexible in meeting my healthcare needs | **0.763** | −0.082 |
| A5...gave me privacy when providing care or treatment | **0.587** | −0.044 |
| A18...gave me positive feedback for my efforts to meet my health needs | −0.075 | **−0.988** |
| A16...discussed changes to my health care with me, as my needs changed | −0.017 | **−0.949** |
| A15...checked with me regularly to see how well my health care was meeting my needs | 0.016 | **−0.938** |
| A17...discussed with me how I felt about coping with my health | 0.030 | **−0.760** |
| A14...explained the results of tests or examinations in an understandable way | 0.238 | **−0.600** |
| Eigenvalues | 7.216 | 11.335 |
| % of variance | 60.13% | 11.12% |
| alpha | 0.917 | 0.938 |

Factors loadings over 0.50 are shown in bold.

per item for the Participation and Responsiveness instruments. Therefore, larger samples must be taken before firm conclusion can be drawn. While follow-up reminders are recommended to increase response rates and reduce bias (Bowling, 2011; de Vaus, 2014), they were not sent because some respondents were still in receipt of health care and might have had concerns about confidentiality, potentially increasing social desirability bias.

There was evidence of age sample-selection and age non-response bias for the Personalization and Responsiveness instruments, suggesting that the age of respondents was not representative of the population of community health service users, although this evidence is weak. Additionally, most respondents' ethnicity was white.

A concern was that older people were slightly less likely to receive or respond to the surveys. Given they are a significant demographic in community settings, they are an important group to consult. Further investigation is required to understand how best to engage older people in quality improvement.

The Participation and Responsiveness instruments required removal of items with >20% missing or DNA responses prior to analysis despite the excellent S-CVI. This suggests that some

**TABLE 7** Revised definitions of person-centred caring as personalization, participation and responsiveness

**Definitions of Person-centred Caring as: Personalization, Participation and Responsiveness.**

**Person-centred Caring** (PCCg) involves those interpersonal behaviours of the healthcare team that support meaningful communication with the person, their family or those close to them. Those behaviours reflect the 'ethics of care' that underpins the caring processes of **Personalization**, **Participation** and **Responsiveness** (P, P&R), which are aimed at meeting the person's health and care needs, whilst feeling 'cared for'.

**Personalization** is the degree to which the healthcare team expresses an interest in the person to establish a rapport and get to know them as a valued individual. This involves interpersonal behaviours that demonstrate: connecting and knowing. **Connecting** is demonstrating a genuine interest in the person, showing them respect and helping them to feel at ease. **Knowing** is getting to know the person, their health experiences and an understanding of how their health affects them.

**Participation** is the degree to which the healthcare team respects and enables the involvement of the person, and those close to them, in their health care. These interpersonal behaviours involve: giving the person understandable information and exploring expectations, concerns and possibilities for their health and wellbeing. It includes sharing decisions, agreeing and carrying out a plan of care together to meet their health and care needs.

**Responsiveness** is the degree to which the healthcare team: monitors, responds to, and evaluates the person's health and care needs. This involves interpersonal behaviours that demonstrate: being attentive and reciprocity. **Being attentive** is being with, or available for, the person to help them coordinate their plan of care and meet their health and care needs. **Reciprocity** is encouraging and supporting the person meet their heath and care needs, whilst jointly monitoring and evaluating responses and adapting the plan of care, as necessary.

interpersonal behaviours may not occur during everyone's episode of care. Imputation and complete case analysis subsequently dealt with other missing responses by case meaning some bias was introduced. The best instruments would have few missing data, unfortunately this rarely happens.

A ceiling affect was present for all instruments. This could represent acquiescence bias or excellent care. There were indications that the Personalization instrument scores differed between groups of respondents according to health status and healthcare teams suggesting that it may be responsive to change.

## 6 | CONCLUSION

The definitions created can guide multidisciplinary teams co-ordinate their practice in a shared framework of Person-centred Caring: This requires them to:

- establish a rapport and understand the person's circumstances, experiences and needs.
- realize a persons' health needs and socioeconomic considerations may affect their capacity to return to independence, limiting choice but not participation.

- recognize a care plan should include acceptability, feasibility and effectiveness in meeting the person's health and care needs.

These instruments could be used as quality tools to address concerns in practice and evaluate quality improvements. For example: the Personalization instrument could evaluate interventions to improve communication skills; patient engagement could be assessed using the Participation instrument; the Responsiveness instrument could monitor if people's needs have been met. The instruments could be issued together. However, they would require individual analyses as they were psychometrically tested this way. Finally, research could explore the relationship between caring and coping or self-care abilities given the association with empowerment and trust.

Further psychometric testing may be required to validate the instruments use: as a combined measure for the same sample; in different and larger populations; and to explore the interpretability.

## CONFLICT OF INTEREST
No conflict of interest has been declared by the authors.

## AUTHOR CONTRIBUTION
All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE): (1) Substantial contributions to conception and design acquisition of data, or analysis and interpretation of data; (2) Drafting the article or revising it critically for important intellectual content.

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## ORCID
*Heather Strachan* [iD] https://orcid.org/0000-0003-2232-5634
*Laura Williamson* [iD] https://orcid.org/0000-0001-6461-2346
*Andrew Elders* [iD] https://orcid.org/0000-0003-4172-4702
*Carina Hibberd* [iD] https://orcid.org/0000-0001-5556-4311

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.