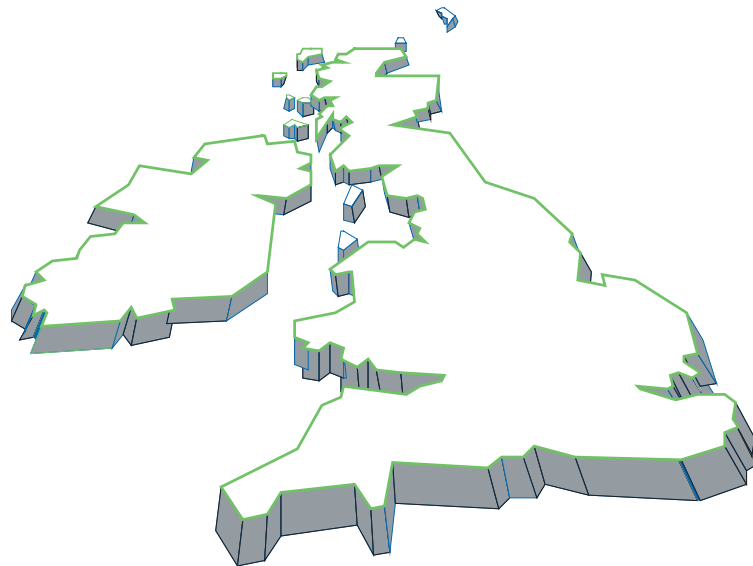




NATIONAL
PRIMARY CARE
RESEARCH AND
DEVELOPMENT
CENTRE

Quality and Outcomes Framework

Patient Experience



October 2007

SAPC

The Society for Academic Primary Care



Patient experience

October 2007

Professor Richard Baker
with support from Dr Umesh Chauhan

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Summary

We believe patient experience remains a priority and the report recommends a number of steps towards maintaining its relevance in patient care.

We suggest the removal of existing indicators PE5 and PE6 and the following additions and changes to the existing indicators.

PE1: The length of routine booked appointments in the practice is not less than 10 minutes. [If the practice routinely sees extras during booked surgeries, then the average booked consultation length should allow for the average number of extras seen in a surgery session. If the extras are seen at the end, then it is not necessary to make this adjustment.] For practices with only an open surgery system, the average face-to-face time spent by the GP with the patient is at least 8 minutes. NO CHANGE FROM CURRENT INDICATOR
PE9: The practice will have undertaken an approved patient survey each year; and the results are made available to patients by information leaflets and poster in the practice, or through a meeting with patient representatives.
PE7: The practice will produce a report that summarises the survey method, the number of patients included and method of recruiting them, the findings, comparison with the findings in the previous 2 years, and describes the actions taken in previous 2 years to improve patient experience in the light of the findings of previous surveys and the action plans and targets devised in response to these surveys. The report will set out plans for the next 2 years to improve patient experience, including explicit and appropriate targets that can be used in the following 2 years to assess the extent to which the action plan is implemented. Deviations from the action plan must be described and explained.
PE8: The practice can produce an up to date list of patient information materials (leaflets, videos, etc) that they make available to patients. The list should include information on all the chronic conditions included in the QOF, acute childhood illnesses, and local resources (including self-help and support groups).

We also recommend that steps be taken to initiate a programme that:

1. Provides for a suite of instruments addressing different aspects of patient experience (including continuity, surveys relating to individual GPs).
2. Keeps instruments up-to-date.
3. Investigates the impact of patient and practice characteristics on levels of experience reported.
4. Prepares advice to practices on standard sampling and administration procedures.

Number of submissions

6

Organisations that submitted

1. Patient & organiser of patient support group (Margaret Gentle, Birmingham).
2. Associate director of primary care commissioning of a PCT (Phil Griffin, Walsall).
3. Chairman of a PCT Patient & Carer Panel (Stephen McCarthy, North Surrey PCT).
4. Patient survey organisation (Michael Greco and David Jenner, CFEP-UK Surveys).
5. Service Improvement officer, PCT (Lisa Drake, Cumbria).
6. PCT Manager (Anthony Rathbone, Telford and Wrekin PCT).

Table 1: Current QOF indicators

	Indicator
PE1 Length of consultations 33 points	<p>The length of routine booked appointments in the practice is not less than 10 minutes. [If the practice routinely sees extras during booked surgeries, then the average booked consultation length should allow for the average number of extras seen in a surgery session. If the extras are seen at the end, then it is not necessary to make this adjustment.]</p> <p>For practices with only an open surgery system, the average face-to-face time spent by the GP with the patient is at least 8 minutes.</p> <p>Practices that routinely operate a mixed economy of booked and open surgeries should report on both criteria.</p>
PE2 Patient surveys (1) 25 points	The practice will have undertaken an approved patient survey each year.
PE5 Patient surveys (2) 20 points	<p>The practice will have undertaken a patient survey each year and, having reflected on the results, will produce an action plan that:</p> <ol style="list-style-type: none"> 1. summarises the findings of the survey. 2. summarises the findings of the previous year's survey. 3. report on the activities undertaken in the past year to address patient experience issues.
PE6 Patient surveys (3) 30 points	<p>The practice will have undertaken a patient survey and, having reflected on the results, will produce an action plan that:</p> <ol style="list-style-type: none"> 1. sets priorities for the next 2 years. 2. describes how the practice will report the findings to patients (for example, posters in the practice, a meeting with a patient practice group or a PCO approved patient representative). 3. describes the plans for achieving the priorities, including indicating the lead person in the practice. 4. considers the case for collecting additional information on patient experience, for example through surveys of patients with specific illnesses, or consultation with a patient group.

QOF achievement 2006/7

The average points achieved per practice for the patient experience domain in 2006/7 was 103.5 points (95.9% of the maximum), compared with 96.9% in 2005/6. The maximum of 108 points was achieved by 7,640 practices (91.3%). 89.9% of practices achieved maximum points in 2005/6.

Summary of previous QOF report

The principal recommendations in our previous report were:

Consultation length

We suggested that the indicator on length of consultations be dropped, and consideration be given to replacing it with an indicator on the availability of double-length appointments on request. The practice should advertise this option to patients, and should provide an audit over a randomly selected 2-week period to record the number of double appointments that were taken up.

Choice of instrument

In order to encourage use of improved administration methods and a better understanding of how to interpret survey findings in different practices, we recommended the use of a single instrument.

Acting on survey findings

We suggested production of a detailed action plan.

Information for patients

We suggested that an indicator on information available to patients be considered. The information would deal with local services, advice on how to contact patient groups (for example, asthma, diabetes, epilepsy), and information on specific problems and conditions.

Background

Policy relevance/priority of area in 2007

We believe patient experience remains a priority. The decision to undertake an access survey in England could be regarded as evidence of policy relevance.

It might be argued that since surveys tend to show relatively high levels of satisfaction with primary care, giving priority to patient experience in the QOF cannot be justified. We reject this argument on the following grounds: (a) surveys in a small number of practices do indicate less than satisfactory patient experience. For example, a small number of practices in the recent access survey were reported as performing poorly; (b) concern has been expressed that the focus in the QOF on management of chronic conditions could impair continuity and aspects of the doctor-patient relationship [1,2]. Maintaining and strengthening the patient experience section of the QOF could help to provide some reassurance on this issue; (c) consumer groups and policymakers continue to promote greater patient involvement and improved experience, a trend that is in accordance with general social trends and expectations; (d) a review of findings of patient surveys in six countries has shown that patient engagement tends to be lower in the United Kingdom (UK) (the

comparison countries were the United States (US), Australia, Canada, New Zealand and Germany). In particular, doctors in the UK were reported as less likely than doctors in other countries to involve patients in decision-making, to give information on self-help or self-management, or to give information about the side-effects of medication [3].

Overview of previous work in the area

There is an extensive literature on patients' experiences of health care. Coulter and Ellins have published a comprehensive recent review [4,5].

Review of existing indicators

Table 2: Current indicators with expert group comments

	Indicator	Comments
PE1	<p>The length of routine booked appointments in the practice is not less than 10 minutes. [If the practice routinely sees extras during booked surgeries, then the average booked consultation length should allow for the average number of extras seen in a surgery session. If the extras are seen at the end, then it is not necessary to make this adjustment.]</p> <p>For practices with only an open surgery system, the average face-to-face time spent by the GP with the patient is at least 8 minutes.</p>	<p>It may be time to consider reducing the number of points to be awarded as most practices manage to achieve this indicator. An alternative suggestion is to verify the average duration of GP consultations through an electronic search.</p>
PE2	<p>The practice will have undertaken an approved patient survey each year.</p>	<p>We are in agreement that practices should continue to undertake surveys of patient experience. However, the number of points for doing a survey should be reduced, and transferred to the response to the survey.</p>
PE5	<p>The practice will have undertaken a patient survey each year and, having reflected on the results, will produce an action plan that:</p> <ul style="list-style-type: none"> - summarises the findings of the survey. - summarises the findings of the previous year's survey. - reports on the activities undertaken in the past year to address patient experience issues. 	<p>We suggest changes to this indicator (see below).</p>
PE6	<p>The practice will have undertaken a patient survey and, having reflected on the results, will produce an action plan that:</p> <ul style="list-style-type: none"> - sets priorities for the next 2 years. - describes how the practice will report the findings to patients (for example, posters in the practice, a meeting with a patient practice group or a PCO approved patient representative). - describes the plans for achieving the priorities, including indicating the lead person in the practice. 	<p>We suggest changes to this indicator (see below).</p>

	considers the case for collecting additional information on patient experience, for example through surveys of patients with specific illnesses, or consultation with a patient group.	
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Patient surveys – methodological issues

We have not received proposals putting forward additional instruments for approval for use in patient surveys. Two survey instruments are currently approved. A wider choice of instruments would enable practices to investigate different aspects of patient experience. It has also been suggested to us that, having undertaken an annual survey for several years with the same instruments, many practices have stopped learning anything new about the experience of their patients. The process has therefore become, for at least some practices, a relatively sterile and routine process with little or no benefit for patients.

Clarity about the goals would be helpful in developing plans for the future of practice patient surveys. If the goal is to promote improvement in patient experience through rewarding practices according to patient survey results, or by creating competition through publication of comparative performance data, the development of a standard national survey that enables comparison between practices would be needed. Evidence would also be needed to show how patient characteristics influence ratings.

If the goal is to generate patient engagement within practices, more rather than fewer patient experience measures are needed. In this approach, the aim is to create and sustain motivation within the practice to understand and respond appropriately to patients' experiences of care. Flexibility in choice of survey instruments would be needed to take account of the concerns of local patients. Practices that understand their patients will want to choose measures that are suitable for their particular circumstances and address issues that are important to their patients. Therefore, this approach requires a range of survey instruments approved for use.

We favour an approach that generates genuine patient engagement in practices rather than one that requires compliance with external measures. However, this approach will require decisions to be made on the range of instruments that can be used, and on how a 'genuine patient focus' is assessed.

The two instruments currently approved (IPQ and GPAQ) are becoming rather out-dated. Whilst they could remain in use for a year or so, revisions will be needed to take account of developments in general practice (for example, the increased role of practice nurses) and also developments in how patient experience is understood (for example, the emerging idea of engagement). The current instruments do not adequately address the concept of continuity, yet concern is often expressed about the impact of the QOF on continuity. Whilst no currently available instrument is suitable for use in the QOF for investigating patient experience of continuity, it would be possible to develop one. (Please see Appendix B for a summary of the literature on continuity of care). Yet development of a new instrument requires time and funding. Factors that deter development of new instruments include: (a) the priorities of the QOF for patient survey instruments may change, and (b) funding for developing survey instruments is not readily available from the new NIHR research programmes.

We recommend that steps be taken, including discussion with the Department of Health, to initiate a programme that

- provides for a suite of instruments addressing different aspects of patient experience (including continuity, surveys relating to individual GPs)
- keeps instruments up-to-date

- investigates the impact of patient and practice characteristics on levels of experience reported
- prepares advice to practices on standard sampling and administration procedures.

A systematic programme of this type is required if the QOF patient experience survey indicators are to promote patient engagement in practices. In the absence of such a programme, the survey indicators will gradually become less useful and may have to be withdrawn.

Review of submitted new indicators

Average length of GP consultations (PE1)

A search of electronic records is proposed to check the average appointment length with GPs. Although the evidence of the benefit of longer consultations is not strong, this change would strengthen the evidence required to show achievement of the indicator. It should be borne in mind that the start and end times of consultations in electronic records are not always accurate for reasons that cannot be avoided (e.g. GP called to another patient or problem in the middle of a consultation), and that some practices operate walk in clinics with short appointments for minor problems.

Making the survey results available to patients

Several submissions encouraged making the survey results available to practice patients. We tend to agree with this proposal. In one submission, discussion with local patient representatives and PCT management was recommended – ‘A lot of practices pay lip service to the survey results’.

The survey content needs review

Submissions included proposing that surveys should be devised in consultation with Patients and Public Involvement committees as they do not focus on some aspects of care important to patients; for example, there should be more questions about nurse care.

Referral to the Expert Patient Programme

One submission recommended referral to the Expert Patient Programme as an addition to ‘Additional Services’. We agree that improved patient education and increased self-management are desirable, and that evidence indicates that there are health benefits [4,5]. This issue is addressed in our proposals.

Patient survey feedback at the level of the clinician

This suggestion is made in one of the submissions. We agree that this suggestion should be considered, and that the evidence is supportive. However, there is as yet little evidence on how the process should be handled – should the results be made public, for example? An option would be a process in which the individual clinician’s results are discussed in appraisal, followed by agreement of an education plan.

Communication skills courses

It was suggested in one submission that attendance at a suitable communications skills training course within the past three years should be rewarded. Whilst the provision of evidence to show compliance with this indicator could be readily provided, we do not recommend this as an indicator. It is a process indicator. Regular training in the absence of

need for training would discredit the indicator. Perhaps the individual clinician patient survey results could be considered in the context of appraisal and a personal development plan.

Immediate referral from GP to clinical specialists

This submission related specifically to patients with vasculitis. We do not recommend a new indicator in this specific area.

Various

Physical access, an interpreter service, a patient participation group, and involving patients in clinical audit were put forward in another submission. Supporting evidence was no provided; some of these issues are addressed by existing indicators and we do not discuss these further here.

Other indicators considered by the expert panel group

During our review, we considered several other indicators, and these are discussed below.

Practice Patient Group

The evidence on patient participation groups is thin, and does not provide guidance on the extent to which groups can be established in all practices, the associated cost, and whether they do encourage improvements in services or experience. In particular, there is little evidence on feasibility and benefits at patient level.

Long appointment slots

Should practices offer extended appointment slots? Many probably already do offer 20 minute appointments with nurses for some conditions, and provide 20 minute appointments with doctors for patients with complex or multiple problems. The evidence on the value of routinely longer appointments is mixed [6,7], and we have not identified any evidence on the effects of allowing more routine 20 minute appointments. Nevertheless, the practical arguments for some longer appointments are quite strong. They enable more time for examinations or consultations for patients with particular problems. However, we have not found evidence on the numbers of such appointments that would be desirable, nor on the characteristics of practice populations that influence the number of longer appointments that should be made available. Thus, it is not possible to estimate the figure X in Table 3 below. Therefore, it is not possible to recommend an indicator on this issue.

Table 3: Length of consultations

	Indicator	Evidence to indicate achievement
PE2	The practice will also offer X/1000 registered patients 20 minute appointments with a general practitioner for the occasional patient with problems that need more time.	If the practice operates an appointment system, survey of appointment system to record the number of appointments booked for 20 minutes per 1000 registered patients. For practices without an appointment system, or mixed system, a survey carried out on 2 separate weeks of consultation length or a computer printout which details the number of appointments of 20 minutes duration or longer.

Suggestions for changes to the patient experience domain in QOF

Evidence to support the proposed new indicators

Replacing PE5 and 6 with new indicator PE7

We agree that the emphasis should be on how the practice uses the feedback from the survey to drive improvements. PE5 and 6 could be made more challenging.

The evidence that patient feedback can lead to changed practise is not strong [9]. However, the available evidence does not consider patient feedback in the context of pay for performance schemes, nor when reinforced by external assessment of the practice's response to the survey findings. Moreover, patients' views of care are sometimes different to those of doctors [10].

Therefore, we recommend that the practice undertake a survey, and that the findings of the survey must be reported to practice patients, either in information on leaflets and posters in the practice or in a meeting with patient representatives, or both. Undertaking a survey alone should no longer attract points.

To qualify for further points, practices should also complete a report that describes precisely how the survey was undertaken (the sample chosen, the response rate, methods of analysis), the characteristics of the respondents, the results (including comparisons with results from previous years), plus plans for service improvements aimed at improving experience. These plans should include explicit targets appropriate to the findings of the survey. For example, a practice must present a plan for improving access if the survey indicates that access is a problem, and the plan must include targets that can be checked for achievement in the following year's report.

The report should also present information to show how the action plans of the past 2 years have been implemented. The requirement may need a phased introduction in the next 1-2 years as practices respond to the new indicator. PCTs will be responsible for reviewing the reports and awarding points accordingly. Practices should be encouraged to make their reports available to their patients.

We considered whether a team of assessors visiting the practice could play a useful role in assessing practices' implementation of their action plans, and level of patient engagement. We found this an attractive option, although potentially difficult to introduce immediately. If work is taken forward with the Maturity Matrix, we recommend that consideration be given to including assessment of patient experience in the context of the Matrix assessment visit. This might consider:

- How well the practice conducted the survey
- The findings and how they compare to the previous year, and any changes made by the practice since the previous survey
- The practice's plans for responding to the findings of the survey
- The priority attached by the practice to improving patient experience.

We support the proposal for a pilot of the Maturity Matrix (please see the organisational report).

Additional indicator: Patient education / information

We recommend the addition of a new indicator in this area (PE8). There is good evidence that patient education can improve outcomes in chronic disease [4,8]. One option we have considered is to require practices to have available sources of information (written, internet).

This could be verified through inspection. This reflects a recommendation made in our previous report, which was not implemented. However, the strength of evidence on this issue has become clearer recently.

A second option is to record on computerised records whether patients have received written patient information material, and if so, whether a computer print out (perhaps personalised to the individual) or a standard booklet. To this could be added an education session with a health professional on the illness and how to manage it. The evidence available does support the provision of written information, although indicates that educational sessions tend to be more effective. An education session could be a fairly simple addition to a chronic disease management consultation.

We agree that practices are unlikely to be able to reproduce the intensive level of patient teaching applied in much of the research, but it would nevertheless be possible to provide more self-management education than at present. Two levels of education can be identified that could attract different levels of reward: 1 - written information (leaflets, personalised print outs); 2 – face-to-face education in the practice. The face-to-face education could be delivered by trained practice nurses in 10- 20 minute consultations, either as extensions to current QOF reviews or in separate sessions for groups of patients. The session could include assessment of the needs of patients for additional education on self-management that might be offered by locality based services.

Whilst there is evidence of the benefit of self-management training on health outcomes, there is only limited experience of this in practices. We suggest that the indicator we propose is introduced in stages, with the information elements (PE7 and PE8 a and b) being introduced this year, and PE8c being introduced next year after some pilot work. Piloting should include exploring which conditions should be selected for inclusion in the scheme.

Table 4: Proposed changes to indicators before the consensus group

PE2: The practice will have undertaken an approved patient survey each year; and the results are made available to patients by information leaflets and poster in the practice, or through a meeting with patient representatives.
PE7: The practice will produce a report that summarises the survey method, the number of patients included and method of recruiting them, the findings, comparison with the findings in the previous 2 years, and describes the actions taken in previous 2 years to improve patient experience in the light of the findings of previous surveys and the action plans and targets devised in response to these surveys. The report will set out plans for the next 2 years to improve patient experience, including explicit and appropriate targets that can be used in the following 2 years to assess the extent to which the action plan is implemented. Deviations from the action plan must be described and explained.
PE8a: The practice can produce an up to date list of patient information materials (leaflets, videos, etc) that they make available to patients. The list should include information on all the chronic conditions included in the QOF, acute childhood illnesses, and local resources (including self-help and support groups).
PE8b: The practice has provided, in the past 2 years, written information to patients with any of the chronic illnesses included in the QOF. This information may be in the form of a standard patient information leaflet or personalised information printed from the practice computer system.
PE8c: The practice provides extended patient education consultation, focused on selected conditions.

Table 5: Recommended indicators following the consensus process

PE2: The practice will have undertaken an approved patient survey each year; and the results are made available to patients by information leaflets and poster in the practice, or through a meeting with patient representatives.	8E
PE7: The practice will produce a report that summarises the survey method, the number of patients included and method of recruiting them, the findings, comparison with the findings in the previous 2 years, and describes the actions taken in previous 2 years to improve patient experience in the light of the findings of previous surveys and the action plans and targets devised in response to these surveys. The report will set out plans for the next 2 years to improve patient experience, including explicit and appropriate targets that can be used in the following 2 years to assess the extent to which the action plan is implemented. Deviations from the action plan must be described and explained.	7A
PE8a: The practice can produce an up to date list of patient information materials (leaflets, videos, etc) that they make available to patients. The list should include information on all the chronic conditions included in the QOF, acute childhood illnesses, and local resources (including self-help and support groups).	7A
PE8b: The practice has provided, in the past 2 years, written information to patients with any of the chronic illnesses included in the QOF. This information may be in the form of a standard patient information leaflet or personalised information printed from the practice computer system. REMOVED	6A
PE8c: The practice provides extended patient education consultation, focused on selected conditions. REMOVED	5E

Workload implications for primary care

The implications of the revisions to the indicators are minimal. The changes to the survey we propose, and the provision of written information, will not have significantly affect workload, although will improve the conduct of surveys and help to ensure that more information is available to patients on clinical conditions. The extension of the information indicator to include self-management education would have workload implications, and require practices to develop additional, often nurse-led, sessions. We have recommended piloting to explore this issue. However, it is important to recognise that the evidence is in favour of education to support self-management.

Implications for other areas of the NHS

There are no significant implications.

Implications for other aspects of QOF

No significant implications unless negotiators decide to explore the idea of piloting these ideas with the Maturity Matrix.

Table 6: Recommended indicators following discussion with IT

PE2: The practice will have undertaken an approved patient survey each year; and the results are made available to patients by information leaflets and poster in the practice, or through a meeting with patient representatives.	Technically feasible.
PE7: The practice will produce a report that summarises the survey method, the number of patients included and method of recruiting them, the findings, comparison with the findings in the previous 2 years, and describes the actions taken in previous 2 years to improve patient experience in the light of the findings of previous surveys and the action plans and targets devised in response to these surveys. The report will set out plans for the next 2 years to improve patient experience, including explicit and appropriate targets that can be used in the following 2 years to assess the extent to which the action plan is implemented. Deviations from the action plan must be described and explained.	Technically feasible.
PE8a: The practice can produce an up to date list of patient information materials (leaflets, videos, etc) that they make available to patients. The list should include information on all the chronic conditions included in the QOF, acute childhood illnesses, and local resources (including self-help and support groups).	Technically feasible.

Table 7: Final List of Proposed indicators

PLEASE NOTE CHANGE IN INDICATOR NUMBERS

PE1: The length of routine booked appointments in the practice is not less than 10 minutes. [If the practice routinely sees extras during booked surgeries, then the average booked consultation length should allow for the average number of extras seen in a surgery session. If the extras are seen at the end, then it is not necessary to make this adjustment.] For practices with only an open surgery system, the average face-to-face time spent by the GP with the patient is at least 8 minutes.
PE9: The practice will have undertaken an approved patient survey each year; and the results are made available to patients by information leaflets and poster in the practice, or through a meeting with patient representatives.
PE7: The practice will produce a report that summarises the survey method, the number of patients included and method of recruiting them, the findings, comparison with the findings in the previous 2 years, and describes the actions taken in previous 2 years to improve patient experience in the light of the findings of previous surveys and the action plans and targets devised in response to these surveys. The report will set out plans for the next 2 years to improve patient experience, including explicit and appropriate targets that can be used in the following 2 years to assess the extent to which the action plan is implemented. Deviations from the action plan must be described and explained.
PE8: The practice can produce an up to date list of patient information materials (leaflets, videos, etc) that they make available to patients. The list should include information on all the chronic conditions included in the QOF, acute childhood illnesses, and local resources (including self-help and support groups).

Appendix A: Methodology

The expert panel identified proposals for new indicators through review of the submissions, discussion with experts in the field, and discussion within the panel. We asked for review of evidence on the effect of length of consultations, and supplemented this with reference to recent published reviews. Drafts of the report were circulated for discussion, leading to preparation of this report.

Expert Panel:

Richard Baker Department of Health Sciences, University of Leicester
Rosemary Humphreys, RCGP Patient Partnership Group representative
Professor Bruce Guthrie University of Dundee
Professor Mary Boulton, Oxford Brookes University
Dr Michel Wensing Radboud University Nijmegen, Netherlands

Consensus Process

The consensus process used a method using aspects of both the Delphi Technique and the RAND Appropriateness Method. There were two rounds of rating. No indicators were added or deleted between rounds. Both rounds were done by email. Panellists were sent a summary report of the available evidence relating to each indicator that they are being asked to rate in round 1. In this respect, panellists are asked to use three criteria when considering their ratings:

- 1). The summary of evidence accompanying the indicators in round 1
- 2). Their own professional experience
- 3). In addition, in round 2, the feedback of ratings from round 1

Indicators were rated on integer scales of 1-9. 1 to 3 means that you think the indicator is not necessary for high quality care, 4 to 6 means that the indicator is an uncertain measure of the quality of care, and 7 to 9 means that you think the indicator is a necessary measure of the quality of care. Necessary care (7-9) refers to care that has a reasonable likelihood of providing net benefit to patients and of improving patient outcomes and/or that it would be improper not to provide the care.

Consensus Techniques are democratic in that the rating of every panellist carries equal weight. Where possible a minimum of 10 experts were chosen for each round who were given one week to read and respond to each round. Those who were known to have submitted indicators were excluded from this process as were the experts involved in writing the report.

Ratings of necessity and consensus

There was a predetermined definition stipulating the criteria by which an indicator would or would not be deemed to be necessary. Within a Consensus Technique, there are two aspects to the rating process for each scale for each indicator: a) the overall panel median rating and, b) the level of agreement within a panel's ratings for each indicator, defined according to the distribution of the panellists' ratings on the 9 point scale. The rating for each indicator therefore contains a number and a letter, as follows:

Rating of necessity

1-9: The number represents the overall panel median for that indicator. An indicator had to have an overall panel median rating ≥ 7 to be rated as necessary.

Rating of consensus

A: Agreement: $\geq 80\%$ of the panellists' ratings within the same 3 point range on the 9 point scale as the overall median

D: Disagreement: 33% of ratings in the range of 1-3 and 33% of ratings in the 7-9 regions for the same indicator

Equivocal: Absence of agreement or disagreement

To be included in a final recommended set of necessary indicators, an indicator had to be rated ≥ 7 for necessity with agreement.

The process involved the following experts in patient experience:

Lisa Cunliffe	Primary Care Commissioning Manager, East Lancashire PCT
Adrian Edwards	Professor of General Practice, Cardiff University
George Freeman	Professor of General Practice, Imperial College London
Dr Paramjit Gill	Clinical Reader in Primary Care Research, Birmingham University
Sue Sutton	QOF Manager & Acting General Practice Services Manager Manchester Primary Care Trust
David Tanner	Senior Manager Contractor Quality & Outcomes, Halton and St Helens PCT
David Taylor	Lay Reviewer for East Lancashire PCT
Dr Paul Thomas	Centre for Study of Policy and Practice in Health and Social Care, Thames Valley University,
David White	GP, clinical QOF Lead Burnley Pendle and Rossendale PCT

Patient Participation Group comments

Mr Anthony Chuter also commented on the report.

It is a very comprehensive detailed report with sophisticated language.

The background is not very informative on the current system. It would be useful to have understood how the current system worked before looking at revisions. What is the purpose and aim of these QOF standards in the area of 'Patient Experience' attempting to achieve or capture and how are the other individual indicators under this banner meeting this?

PE1 is, by the report's own admission, not an accurate indicator so a more accurate indicator needs to be found.

I would suggest that you don't use PPI groups but form fresh focus groups each time and in each practice by a random recruitment.

I would encourage informing patients what the EPP is, what it does and what it could do for the individual.

I would like to see patients actively involved in the reviews and assessments.

Acknowledgments

We would like to thank the following people for their help in producing the NPCRDC based reports:

1. Ms Annette Barber for administrative support.
2. Miss Ella Gaehl (help with analysis of the consensus process).
3. Dr Stephen Campbell (advice with the overall consensus process).
4. Mr Alan Payne, Business Analyst at Primary Care Team (GMS Payments Project) NHS Connecting for Health.

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Appendix B: The role of continuity of care in primary care: A narrative literature review

Lynda Tait and Helen Lester

Summary

Background

Continuity of care has been widely viewed as an indicator of the quality of care in primary care. Recent changes to health care delivery and organisational changes in primary care present a challenge to the achieving continuity.

Objectives

To provide an overview of research examining the role of continuity of care within primary care settings from national and international perspectives.

Method

A search of computerised databases, including MEDLINE, EMBASE, CINAHL, PsycInfo, SSCI and the Cochrane Library Database of systematic reviews, was conducted to identify studies examining continuity of care in primary care. Exclusion criteria were studies conducted within inpatient settings, or focused on the primary care/secondary care interface.

Results

Most patients would like to see the same doctor however, there are some patients who would sacrifice their preference to see the same doctor depending on the reason for the visit and there are some patients to whom rapid access matters more than continuity of care.

Continuity of care improves the process of care though not the health status outcomes of patients with some chronic conditions. There are a limited number of well-designed instruments but the majority of tools are unable to directly measure continuity of care, reflecting the complexity and multidimensional nature of continuity of care.

Conclusion

There is insufficient evidence to conclude that continuity of care is associated with significant improvements in health outcomes but there is good evidence that continuity of care can improve some aspects of the quality of care delivered in primary care settings. There is also good evidence that a majority of patients value continuity of care but that it is valued more by older patients, patients with chronic illness and patients consulting with more serious illnesses. Most existing measures of continuity reflect health system attributes rather than measuring continuity itself. Progress has been made in developing patient-based condition specific measures of continuity; however, further research is required to provide reliable and valid measurement tools that are easy to use in primary care and reflect the patient's perspective.

Executive summary

Background

Objectives

1. To provide a brief overview of the policy context of the place of continuity of care in UK primary care.
2. To provide a summary of the evidence base on the conceptual elements of continuity of care.
3. To highlight tensions where they exist between access and continuity in a primary care setting; changes in health workforce and continuity of care, and the links between quality of care and continuity.
4. To summarise patients' views of continuity of care and, in particular, to provide a summary of the evidence base on patients for whom continuity of care within primary care is of most and least importance.
5. To provide a summary of the methods of measuring different aspects of continuity of care from a UK and international perspective.

Methods

The term *continuity of patient care* combined with permutations for describing primary care and key subject [MeSH] terms and keywords for describing associated issues relevant to the objectives were used to search five primary research databases and a secondary research database, together with hand searching of key references up to April 2007. Abstracts and full-length papers were independently reviewed. No quality restrictions were applied to the inclusion of studies in order to provide an overview of the literature in a short timeframe. Research articles that did not match the aims of the review were excluded.

Results

The initial search of the literature identified 3,144 studies of possible relevance to the objectives. After titles and abstracts were searched, 341 references were obtained for further analysis.

The key findings from the literature are as follows:

1. There have been policy developments that have the potential to reduce continuity of care. Changes around access to primary care have the potential to fragment care.
2. Continuity of care is a multidimensional and complex construct. Despite decades of research, the term has many meanings and diverse ways of measurement. Little progress has been made in developing tools with established psychometric properties.
3. Much research concerned discussion of definitions of continuity of care. The majority of studies on continuity of care were concerned with patients' views and experiences of continuity of care and the relationship of continuity of care to the processes of care. Less research concentrated on the effect of continuity of care on patient health outcomes, other than patient satisfaction, or on evaluating interventions or cost comparisons.
4. Published research is concentrated at the lower levels of the hierarchy of evidence, with few randomised controlled trials or interventions in which continuity of care has been examined. The majority of studies employed qualitative research designs or were based on surveys. These are useful both as a means of exploring patient

experiences and views and can be informative in providing further explanation or for conducting pilot studies, and complementing experimental research.

5. Considering the wide scope and extensive literature of this research field, few secondary analyses have been conducted, with one narrative review and no systematic reviews on patients' preferences and views about continuity of care.
6. Research evidence supports the hypothesis that patients value continuity of care, particularly older age groups and those with chronic or long-term illnesses. Young people and those with acute or less severe illness are more likely to trade off continuity of care against rapid access.
7. More research needs to be undertaken on how patient preferences are formed and to identify factors that affect patient preferences for continuity of care. There has been little research examining the views of minority ethnic patients or those with mental health problems. Culturally specific questionnaires have not been developed.
8. The heterogeneity of research and use of different measures has made it difficult for researchers to identify the impact of continuity of care on health outcomes.
9. There is some research evidence to show that continuity of care has the greatest impact on process issues.
10. Early studies on the effect of continuity of care have been restricted by the availability of validated measures from the perspective of patients, as well as the problem of weak research designs. As a result, there is little evidence on the impact of continuity of care on health outcomes.

Methodological Limitations

This review may have been limited by selection bias resulting from the selection of studies for inclusion by a single reviewer and the grey literature was not searched, which may have contributed to publication bias. The methodological quality of primary studies was not assessed, due to time constraints.

Conclusions

Studies examining patient outcomes in relation to continuity of care in primary care settings suggest that some patient outcomes are improved as a result of increased continuity of care. Although most patients value continuity of care, it is most valued by older patients and by patient groups with complex or chronic medical conditions.

Background

Continuity of care has been considered a core aspect of general practice. In the health services literature, although the term *continuity* has multiple definitions, it has commonly been described in terms of the relational aspects of the delivery of health care, the transfer of information between healthcare providers and the coordination or integration of care needed to support collaborative care^{1 2 3 4}. Quality improvement is an important issue in primary health care, partly in response to evidence of deficiencies and variation in the quality of medical care provided⁵. Continuity of care has traditionally been understood as a means of improving health care delivery and the concept has been linked to quality assessment through research using Donabedian's⁶ classic 'structure', 'process' and 'outcome' model for assessment of quality of care. Based on this conceptual framework, the relationship between quality of care and the role of continuity of care has been studied using process of care variables, patient health outcomes, and costs of care endpoints.

The role of continuity of care in primary care is a key policy issue, since researchers and policymakers are interested in understanding the implications of primary care health policies (e.g. widening access to primary care) on the delivery of services and on the quality of care provided. Recent changes to health care delivery, in the form of National Health Service (NHS) walk-in centres, NHS Direct, out-of hours services, community pharmacies, specialisation within general practice and organisational changes in primary care, such as the growth in size of primary health care teams, present a challenge to achieving aspects of continuity in primary care^{7 8}. The development of a new quality indicator within the Quality and Outcomes Framework specifically for continuity of care is therefore an opportunity to address an important obstacle to quality improvement in primary care. Threats to continuity of care may also come from patients themselves. Patients may trade-off continuity of care for convenience and faster access to primary care health care⁹, resulting in the fragmentation of care. This issue highlights the need to consider the importance of examining continuity of care from the patient's perspective.

Important questions have been raised by a number of authors: do all patients value all components of continuity of care, and do differences of views exist on the relative value of continuity of care and other health care system level factors according to patient group? However, good quality research on patient perceptions of the importance of continuity of care, why it matters and how this varies by different patient groups has been limited. Recently, several studies have been conducted with the aims of understanding patients' experience of continuity of care, what continuity of care means to patients, determining patients' preferences and views about different aspects of continuity of care and why it is important to them^{7 9 10 11 12}.

The need for better understanding of continuity of care, from provider and patient perspectives, has been recognised; and has resulted in the NHS Service Delivery and Organisation (SDO) Programme commissioning of a number of studies designed to examine the effect of continuity of care on outcomes in chronic conditions, reviews of patient and carer perspectives, as well as scoping reviews of the continuity of care literature^{13 14 15 16}.

A number of literature reviews focusing on the concept and definition of continuity of care, on the instruments intended to assess continuity of care and the relationship between continuity of care and patient outcomes have already been published^{12 17 18, 19 20-24}. This review builds on and synthesises this body of literature. It considers the role of continuity in primary care, its definitions and tensions between aspects of primary care and continuity and provides an overview of the effectiveness of continuity of care on processes and outcomes of patient care, particularly for chronic medical conditions. It also reviews the evidence to determine patients' views on the relative importance of aspects of continuity of care and identifies the approaches used to measure continuity of care in primary care settings.

Aims and scope

The purpose of this review was to provide a research overview of the continuity of care field in primary care (general practice). Although a systematic approach was adopted, it was not possible within the timeframe (three months) to provide a detailed, systematic review of each of the main topic areas. Specific questions were addressed in the overview of the literature.

The following five related objectives are addressed within this review:

1. To provide a brief overview of the policy context of the place of continuity of care in UK primary care settings.
2. To provide a summary of the evidence base on the conceptual elements of continuity of care.
3. To highlight tensions where they exist between access and continuity in a primary care setting, on changes in health workforce and continuity of care, and the links between quality of care and continuity.
4. To summarise patients' views of continuity of care and, in particular, to provide a summary of the evidence base on patients for whom continuity of care within primary care is of most and least importance.
5. To provide a summary of the methods of measuring different aspects of continuity of care from a UK and international perspective.

Methods

Search strategies

For the purposes of the overview of the literature, a preliminary scoping search was undertaken using MeSH terms and key words. These were 'exploded' to identify articles relevant to the five main topic areas related to continuity of care. A systematic literature search was then undertaken in electronic databases using search terms: continuity of patient care*, professional-patient relations, physician-patient relations*, family practice*, primary health care*, quality of health care*.

Database searches

Electronic searches of MEDLINE (Ovid 1950 to 2007), EMBASE (Ovid 1980 to 2007) CINAHL (1982 to 2007), PsycINFO (1985 to 2007) and the Social Sciences Citation Index databases were undertaken and a search of a secondary research database (Cochrane Database of Systematic Reviews) and the Department of Health website were conducted to identify existing reports and systematic literature reviews. The Social Sciences Citation Index database was searched to trace citations in key papers. Articles were restricted to English language journals, published in the period from 1950 to 2007, with the search conducted in April 2007. Bibliographies of retrieved articles were searched in anticipation that database searches may have missed relevant articles.

Selection of articles for review

The initial search of the literature identified 3,144 publications of possible relevance to the study objectives. It was not feasible to review the full text of all these articles within the timeframe and therefore articles were scanned for relevance on the basis of an initial examination of the title, key words and abstract when available. Studies were included if the abstract reported on research that specifically focused on any of the five review topic areas, including review articles on continuity of care within the context of primary care. This screening process eliminated numerous articles, many of which were unrelated to primary care or were editorials or letters. Articles were also excluded that focused on continuity of

care related to inpatient settings, shared-care, transition from hospital, or the interface between primary and secondary care. 341 full texts articles were then viewed for final inclusion. Full-text articles were also obtained where systematic reviews failed to provide sufficient study details.

Data extraction and article synthesis

A checklist was used to appraise the methodological quality of systematic reviews²⁵. However, time constraints and fulfilling the purpose of the review, which was to provide an overview of the broad field of continuity of care, precluded systematic analysis of the methodological quality of primary studies. Descriptive, methodological and outcome data were extracted from studies and, where appropriate, the results pooled in a qualitative (narrative) manner.

Objective 1: To provide a brief overview of the policy context of the place of continuity of care in UK primary care settings.

Tensions between access and continuity

Recent Government policy has emphasised improving access to medical care²⁶ with proposals to guarantee access to a health professional within a target of 24 hours and a GP within 48 hours, and several proposals in the 2006 White Paper *Our health, our care, our say: a new direction for community services*²⁷ for providing a wider range of services in primary care. New points of patient access to healthcare have been introduced including NHS Direct, Walk-in centres and community pharmacies²⁸. The recent interim report on the future of the NHS (October 2007) further emphasised the importance of accessing primary care services out of hours,

The new General Medical Services (GMS) contract²⁹ originally included a 50 points access bonus within the Quality and Outcomes Framework (QOF) for achieving the 24/48 hour access target^{30 31} although the access points were removed and replaced by a country specific access focussed enhanced service in the 2006 revision of QOF.

One of the main criticisms of QOF has been that it may have altered the dynamics of the doctor patient relationship and lead to an increasing focus in biomedical issues within consultations. Continuity of care has often been used as an exemplar of an area that could be incentivised and might address part of the 'tick box' approach of the framework although there are worries that it is such a complex issue, reducing continuity to a measurable variable may fail to capture its meaning and value at consultation level.

Objective 2: To provide a summary of the evidence base on the conceptual elements of continuity of care.

Definitions and Models of Continuity of Care

Continuity of care is regarded as one of the distinguishing features of general practice³. However, despite an extensive literature, continuity of care is not an easy concept to define. This definitional challenge and the diversity of definitions in the literature arise, in part, from the different perspectives of researchers. The diversity reflects differences of emphasis, meaning and terminology used. There is confusion around the definition of continuity of care and there is no agreed terminology, where different terms have been used to mean the same thing, and descriptions of continuity of care range from a single concept to multidimensional models with varying numbers of dimensions. Although definitions of continuity of care within this literature lack clarity and consistency, a tentative shared view has emerged within the continuity of care field on which key domains and models of continuity are most important to general practice.

Numerous discussion papers and reviews synthesise the conceptual research on continuity of care^{12, 16, 22-24, 32-36}. A recent systematic review of the literature published between 1986 to 1996, provided a summary of the explicit definitions of continuity of care identified in the literature²⁴. In view of the substantial progress made by previous reviews to bring clarity to the field, an historical overview of this enormous literature would not be productive. Therefore the focus in this section is on contemporary viewpoints of the meaning of continuity of care with relevance to primary care.

Freeman et al (2001)¹³ reviewed the range of definitions of continuity of care in the field of healthcare and suggested that from across the different perspectives the following definition captured the most important element of continuity of care:

“the experience of a co-ordinated and smooth progression of care from the patients' point of view (*experienced continuity*)”.

Freeman et al's (2001)¹³ core definition expresses continuity of care at the patient level: how patients experience care that incorporates their values, priorities and experiences of provided continuity. This model of continuity further distinguishes between how continuity is experienced by patients and continuity in the delivery of care. Therefore, this approach views 'experienced continuity' as an outcome rather than as a process of service provision, an observation that has been proposed by other authors³⁷. In order to achieve 'experienced continuity', five process-structural variables situated at the health care system level were proposed as possible determinants of 'experienced continuity'. According to this definition, the patient experiences continuity of care in five different ways:

1. Excellent information transfer following the patient (continuity of information)
2. Effective communication between professionals and services and with patients (cross-boundary and team continuity)
3. To be flexible and adjust to the needs of the individual over time (flexible continuity)
4. Care from as few professionals as possible, consistent with other needs (longitudinal continuity)
5. To provide one or more named individual professionals with whom the patient can establish and maintain a therapeutic relationship (relational or personal continuity).

Subsequently, a Canadian research group reviewed the published literature on different perspectives that inform definitions of continuity of care within primary care, mental health care, nursing care and care for specific conditions and identified common themes across disciplines²³. Aspects in their description of common themes identified across disciplines are

similar to the elements described by Freeman et al (2001) ¹³. However two core elements were proposed in their model as the basis for continuity of care:

“Continuity can only exist as an aspect of care: That is experienced by an individual; and That is received over time”.

The focus in this definition is also on continuity of care experienced by the patient but includes the concept of time, often referred to in models of continuity within the literature as *chronological* or *longitudinal* continuity ³². The authors, in agreement with Freeman et al (2001) ¹³, distinguish between how continuity is experienced by patients and other attributes of provided care, linking ‘experienced continuity’ to three distinct types of continuity of care:

1. *Informational continuity*, ‘the use of information on past events and personal circumstances to make current care appropriate for each individual’
2. *Management continuity*, ‘a consistent and coherent approach to the management of a health condition that is responsive to a patient’s changing needs’
3. *Relational continuity*, ‘an ongoing therapeutic relationship between a patient and one or more providers’.

Relational or interpersonal continuity and longitudinal continuity have gained widespread recognition as the most important components of continuity to traditional general practice ^{4, 12, 13, 33, 38}.

The definitions and models reviewed are derived from the perspective of researchers; what continuity of care means to patients, GPs or other health professionals has received less attention. The definitions are based on descriptive work rather than the product of theoretical models or empirical research. Few studies have empirically examined the importance of each of the continuity of care components relative to each other ¹⁶. Freeman’s model of continuity of care has provided the basis for subsequent work on exploring patients’ experiences and values concerning continuity in specific medical conditions, resulting in the development and psychometric evaluation of continuity measures in diabetes ³⁹ and cancer care ⁴⁰, and providing evidence that continuity of care is a multidimensional construct.

Objective 3: To highlight tensions where they exist between access and continuity in a primary care setting; changes in health workforce and continuity of care and the links between quality of care and continuity.

Access to Care and Health Workforce Changes

Recent changes in the organisation of primary care and new ways of working in UK general practices have transformed how patients access health care. Many practices now operate an advanced access model, similar to the advanced access patient scheduling model operated in the USA⁴¹, replacing a restricted booking system with pre-bookable appointments. The extension of nursing roles in primary care, particularly in relation to assuming responsibility for chronic disease management, reflects a policy choice specific to the objective of addressing capacity restraints to alleviate access problems⁴².

Although these changes may offer more flexibility and convenience for patients,⁴³ improving patient choice of ways to access care may also mean that patients are less likely to see the health professional or usual GP of their choice²⁸. This may be more problematic for patients who attend general practices more frequently than those who are infrequent attendees⁴⁴ and for chronic illness management, which necessitates continuous care²⁸. A study of an advanced access initiative in the UK found that one of the main concerns GPs raised was the potential adverse effect of the trade-off between rapid access and continuity of care⁴⁵.

In England and Wales, the implementation of the new GMS contract in 2004²⁹ may also make achieving continuity of care more difficult within primary care. For example, the new GP contract has led to change in the provision of out-of-hours services with PCOs now responsible for provision of out of hours care. There is evidence that older people are reluctant to make use of out-of-hours services, preferring instead contact with a familiar doctor⁴⁶. Patients can also now choose, at their convenience, to access NHS Direct and Walk-in clinics for first contact primary care^{4, 28, 42}. These organisational changes may have the unintended effect of increasing fragmentation of care and reducing continuity of care⁴.

Quality of care and Continuity of Care

In the healthcare literature, continuity of care has been viewed as an indicator of the quality of care. It is generally assumed that a higher quality of medical care and positive effects on clinical outcomes are associated with greater levels of continuity of care, particularly interpersonal continuity of care⁴⁷⁻⁵⁰. Furthermore, lack of continuity of patient care may influence the diagnostic process in primary care, contributing to delayed diagnosis of medical conditions⁵¹. One hypothesis suggests that the accumulated knowledge about patients' medical and personal histories is a result of interpersonal continuity and consequently leads to better medical care and clinical outcomes^{50, 52}. Donabedian's quality of care model^{6, 53} has received wide acceptance in the health care literature, and has been used in the continuity of care field as a framework for building evidence on the relationship between continuity of care and the quality of care.

The following synthesises the results of empirical research on a range of process of care and patient health outcomes appropriate to continuity of care in primary care. Several relevant studies have focused specifically on patient satisfaction as an indicator of the quality of clinical care and on the quality of clinical care for long-term chronic conditions (Table 5). The majority of studies examining the effect of continuity of care on the quality of patient care and outcomes have been conducted in the United States.

Synthesis of Systematic Reviews on the Relationship of Continuity of Care to Outcomes

Characteristics of Systematic Reviews

Six reviews were identified that matched the inclusion criteria (Table 1). Of these, four were systematic reviews^{17-19, 21} and two were general reviews^{22, 54}. The reviews focused on quality of care (for example, patient health outcomes)^{17, 19, 22}, patient satisfaction¹⁸, cost of health care^{17, 19} and health outcomes in particular target groups (for example, older patients or children and adolescents)^{21, 54}. There was a large overlap between the reviews, with many primary studies included in more than one review.

The exclusion criteria used in the four systematic reviews were similar. However, the methodological quality of the reviews varied. Although the systematic reviews addressed appropriate and focused questions and clearly described the methodology used, three reviews^{18, 19, 54} were based on a limited literature search of one major database only (Medline). Their search strategy may have missed important primary studies. An assessment of study quality was not reported in one of the systematic reviews¹⁷ and in both of the narrative reviews^{22, 54}, and the quality of the studies included in two of the other systematic reviews^{18, 19} was evaluated by grading evidence on five design features, including credibility of continuity measurement, appropriateness of study design to answer the research question, outcomes applicable to family physician practices, credibility of outcome measurement and generalisability of findings to other settings. Therefore, it is not clear if particular design features of the reviewed studies were examined; for example, randomisation concealment, blinded assessment of outcomes, and whether contamination was a problem in some settings, limiting the ability to evaluate the evidence base to support the conclusions of the reviews.

None of the reviews conducted formal meta-analyses of the results of the studies due to the heterogeneity of the studies included in the reviews with respect to diverse patient populations and differences in continuity of care definitions and measurement techniques and measurement of other study variables.

Results

Range of outcomes reported: A wide range of process of care and fewer patient health outcomes were found in studies published from 1966 to 2005 considered by systematic reviews^{17-19, 21}. As an indication of the extent of the clinical diversity in the outcomes identified in the empirical literature examining the impact of continuity of care on patient outcomes, one systematic review identified 81 distinct care outcomes in 40 primary studies^{19, .}. Studies of the relationship between continuity of care and the process and outcomes of medical care typically reported a combination of data relating to patient satisfaction with care, delivery of preventive care, chronic illness management indicators and other related process outcomes (for example, impact on quality of doctor-patient relationship). This approach has the potential to show how continuity of care effects can vary across different process outcome domains. However, improvements in health status outcomes is harder to demonstrate, which is often the intended aim of studies, than process of care outcomes. Assessment of organisational structures, such as performance assessment, staffing or information systems, was not considered by any of the reviews.

Process of care and patient outcomes identified in the systematic reviews included:

Process of care outcomes:

Preventive care

Doctor-patient relationships

Papanicolaou tests
Breast examinations
Immunizations
Ophthalmology care
Blood and thyroid tests
Blood pressure, weight and smoking status
Patient enablement
Professional competence
Perceived quality of care
Maternity care
Access to care

Patient outcomes:

Patient satisfaction
Quality of life
Blood pressure, lipid, and glycemic control
Neonatal morbidity
Newborn mortality
Treatment compliance

Patterns of health service utilisation:

Hospitalisation duration and incidence
Visits to emergency departments

The most commonly reported outcomes related to use of health services (hospitalisation rate, risk and duration) and preventive care. Data on inpatient care may not provide a useful way of measuring the benefits of continuity of care in primary care settings as they are influenced by a wide range of other factors such as availability of resources, clinical practice and the severity of medical conditions.

Elderly patients: A Canadian systematic review examined the evidence that continuity of primary care results in better clinical outcomes among older people with chronic diseases²¹. Identifying only five studies of sufficient quality for inclusion, this review concluded that there were insufficient data to draw firm conclusions for the benefit of continuity of care for older people, highlighting the need for further research focusing on this particular patient population.

Menec et al⁵⁵ examined the relationship between continuity of primary care and hospitalisations in a survey study of older adults living in Canada. These authors found that high continuity of care, defined as 75% of all visits to the same family physician, was associated with reduced odds of being hospitalised for ambulatory care-sensitive conditions (e.g., pulmonary tuberculosis, asthma, congestive heart failure, hypertension, angina, diabetes, bacterial pneumonia) relative to patients with a low continuity of care profile.

Children and adolescents: A narrative review was identified that examined continuity of care in general paediatric ambulatory care, including studies on continuity within primary care practice⁵⁴. This review searched the Medline database only and included articles published between 2002 and 2004 to compare with previous published research on the relationship between continuity and patient outcome. There was considerable overlap of the included studies with three other reviews¹⁷⁻¹⁹. The authors found that recent research added to the evidence that physician continuity had a significant positive effect on decreased emergency department use during early childhood, improved coordination of care for children enrolled in a primary care clinic and higher ratings of patient and parent satisfaction with care within the Canadian health care system.

Patient Satisfaction: Although patient satisfaction is a complex concept and satisfaction of care determined by numerous factors⁵⁶, it has been used as a proxy measure of healthcare quality and healthcare outcome in continuity of care research. The review by Saultz and Albedaiwi¹⁸ specifically examined the effect of continuity of care on patient satisfaction and the review by Cabana and Jee¹⁷ examined patient satisfaction as one of several outcomes studied. There was considerable overlap of studies included in the two reviews. Both studies reported improvements in patient satisfaction when continuity of care was increased.

Saultz and Albedaiwi¹⁸ included 22 articles in their review, and found significantly improved patient satisfaction for low-income paediatric patients receiving care in a comprehensive paediatric clinic when compared to a walk-in clinic in one clinical trial. Similar results were found in another clinical trial in which low-income paediatric patients were randomly assigned to a clinic with continuity compared to a walk-in clinic. Similar results were reportedly obtained in two further randomised trials, one examining older males in the USA and the other examining Australian women receiving care from midwives. This review concluded that although continuity of care was associated with improved patient satisfaction, there were serious shortcomings in all four trials in relation to uncontrolled differences between study groups and failure to use standardised continuity of care measures in two of the trials.

Despite reporting varied study quality and the use of diverse definitions and measurement of patient satisfaction and continuity of care, Saultz and Albedaiwi¹⁸ concluded on the basis of the four clinical trials considered that there was evidence of a consistent and significant positive relationship between continuity of care and patient satisfaction.

Saultz and Albedaiwi¹⁸ also examined the results of four cohort studies and 12 cross-sectional surveys or correlational studies, which yielded 13 positive associations between patient satisfaction and continuity of care, with the exception of three studies finding no relationship. It was noted, however, that all of the studies were limited by flawed methodology in relation to confounding and the use of inappropriate or inadequate measurement techniques. In addition to reporting on two articles included by Saultz and Albedaiwi¹⁸, two additional cross-sectional studies were identified by Cabana and Jee¹⁷, with the authors reporting a consistent positive association between continuity of care and patient satisfaction. There therefore appear to be an association between patient satisfaction and improved continuity of care.

Varied process and clinical outcomes: One systematic review¹⁹ on the relationship between interpersonal continuity of care and various quality of care and patient outcomes included many of the studies identified in a previous review on patient satisfaction¹⁸. The authors included 40 studies, which investigated outcomes in a variety of population subgroups, and found that out of 81 distinct care outcomes identified, 51 outcomes were positively related to interpersonal continuity of care. The exceptions were two studies that reported negative associations between interpersonal continuity of care and quality of care and 28 outcomes that were associated with either mixed or non-significant associations. The majority of outcomes reported focused on preventive care, followed by maternity outcomes, health service utilisation (e.g., hospitalisation rates), chronic illness care (e.g., blood pressure or glucose control), and quality of doctor-patient relationship. The review lists major methodological limitations to the conduct of most of these studies. The quality of previous studies has implications for researchers who often cite these studies as evidence in support of unequivocal benefits of continuity of care. Furthermore, the majority of studies included in the review were conducted in the 1960s and 1970s, prior to the development of quantitative measures of continuity.

Chronic conditions: Among the reviews that focused on the relationship between continuity of care and patient outcome, two reviews reported on studies that examined the effect of continuity of care on patient outcomes in chronic conditions^{17, 19}. Several articles were

identified that studied continuity of care and health outcomes in chronic conditions but were not considered by these reviews or the publication date extended beyond their systematic search of the literature. The results of these studies are briefly summarised and presented in Table 2. The majority were descriptive or observational studies; many with weaker designs than others, and one randomised controlled study. The majority of the studies measured continuity of care using commonly used continuity of care indices and patient reported preference to see a usual doctor.

The results of considered articles were mixed, with studies demonstrating a significant positive association between continuity of care and receipt of preventive services⁵⁷⁻⁶¹, and other studies finding either no significant relationship between continuity of care and delivery of preventive services⁶²⁻⁶⁴ or an inverse relationship⁶⁵. Studies investigating relationships between continuity of care and diabetic control observed either no relationship^{14, 66-68}, no decrease in quality of care associated with discontinuity of care⁶², discontinuity associated with early recognition of diabetes⁶⁹ and high glycaemic levels at diagnosis⁷⁰, or continuity associated with less likelihood of diabetes remaining unrecognised⁷¹, and greater patient satisfaction^{14, 72}. Continuity of care was also found to be positively associated with greater patient satisfaction^{63, 73}, reduced likelihood of hospitalisation for older patients⁵⁵, reduced emergency department use for adults⁵⁹, antidepressant continuation⁴⁹ and high continuity found to be less common among hip fracture patients⁷⁴, but non-significant associations were found in other studies on quality of care⁷⁵, doctor-patient discussion⁷⁶, medication compliance⁷⁷ and hospitalisations and emergency department visits in adolescents with asthma⁷⁸.

QoF specific conditions

Asthma: Few studies have been conducted on the relationship between continuity of care and asthma. Two systematic reviews^{17, 19} reported that lower continuity of care was associated with a higher risk of emergency department visits and hospitalisations in children with asthma. Similar results were found in a Canadian study examining levels of continuity of care in adolescents with asthma⁷⁸. In this longitudinal cohort study, continuity of care was low among adolescents with asthma, which was associated with a higher risk of emergency department visits and hospitalisation for asthma. This study used a generic measure of continuity of care and a complex disease-specific index of continuity of care specifically designed for this study, which was based on both the number of medications prescribed for asthma and the number of physicians prescribing the medication. The authors suggested that measuring continuity of care with a disease-specific index may explain the discrepant findings with another study examining adolescents with asthma. The literature therefore suggest that increased continuity may perhaps decrease A and E visits in children and adolescents.

Cancer Screening:

Cabana and Jee¹⁷ reported improvement in receipt of preventive services in patients receiving increased continuity of care, including increased likelihood of breast and cervical cancer screening in one cross-sectional study. A study comparing patients in family practice settings with high and low continuity of care in Cleveland, USA, found that higher continuity of care was associated with better adherence (rates increased by 27% relative to the usual care group) to recommended screening flexible sigmoidoscopy⁶¹. A study from South Carolina, USA, found that continuity of care prior to diagnosis of breast cancer was related to receipt of breast cancer screening⁶⁰. However, continuity of care was not significantly related to earlier detection and in reality, there are many more potent levers to increase cancer screening that incentivising continuity of care.

Coronary Heart Disease: Four systematic reviews^{17, 19, 21} identified the same randomised trial of sufficient quality for inclusion. This study (776 men aged 55 and over with cardiovascular

disease and respiratory disease) compared provider discontinuity and provider continuity veteran groups. Provider continuity was associated with only four out of 17 measures: shorter average hospital length of stay, fewer emergent hospital admissions, fewer hospital days and intensive care days. No significant difference was found on a number of process of care variables relating to clinic visits, specialty referrals, or receipt of preventive care services concerning blood pressure measurement, weight and smoking status assessments. However, this was a study examining older veteran males in the US and therefore the results cannot be generalized to other groups.

Similar non-significant findings have been found in a retrospective cohort study of patients with coronary heart disease⁷⁵. This study examined the relationship between continuity and the quality of care delivered, finding a positive relationship between increased continuity and patient satisfaction but no association with improved clinical care in the secondary prevention of coronary heart disease. However, the results should be treated with caution as the study was based on patients from one practice and continuity measurement limited to the percentage of consultations in the previous 12 months.

Diabetes: The relationship between continuity of care and the quality of care received by people with diabetes has been the focus of several studies, the findings of which are mixed^{17, 19}. In a study using process measures (proportion of visits to patient's usual primary care provider) as an indicator of quality of care delivered, patients in the USA diagnosed with type 2 diabetes mellitus who had visited their usual providers within the past year were more likely to have received eye and foot examinations, had blood pressure measured and lipid levels analysed⁴⁸. Continuity and quality of care were also significantly associated, after adjusting for demographic variables and health status, however the strength of the correlation was weak ($r = .148$). In contrast, no association between provider continuity and diabetes monitoring tests was found in a cross-sectional analysis of claims data⁶⁸.

Epilepsy: Only one study was identified that considered epilepsy in relation to continuity of care. This study investigated the epilepsy-related experiential and psychosocial benefits as indicators of better epilepsy care associated with interpersonal continuity of care⁷⁶. This cross-sectional study, in which 99 patients aged 15-64 years with active epilepsy were interviewed, found improved patient ease enabling patients to talk to their physician. Continuity was associated with discussion of personally important issues with a usual doctor; however, discussion of epilepsy was not significantly associated with continuity of doctor. Continuity of care was calculated using an index of usual provider continuity and defined as the percentage of the 12 most recent consultations with the most often consulted doctor.

Learning Disability: Although the need to widen access to primary care for people with learning disabilities has been recognised in health policy⁷⁹, no literature examining the relationship between continuity of care and outcomes in people with learning disabilities was identified.

Mental Health: Empirical evidence to support a beneficial effect of continuity of care on service user outcomes in mental health services is limited by a lack of studies⁸⁰⁻⁸². Similarly, few studies have examined the relationship between continuity of care and outcomes in primary care mental health.

A well-designed randomised controlled trial (RCT) conducted in 18 primary care clinics in eight US healthcare organisations⁸³ examined the effectiveness of collaborative care management for depression in late life. This study was included as an example of the potential benefit of continuity of care to improving healthcare for patients with mental health problems. Collaborative care was defined as shared care delivered by the patient's primary care doctor, a primary care nurse and a consulting psychiatrist in the primary care setting. The results indicate significantly improved clinical outcomes and quality of life for patients

receiving the intervention compared to standard care. However, the authors were unable to report on the specific components that may have contributed to the effectiveness of collaborative care due to the study design; relapse prevention and an enduring therapeutic relationship in primary care were identified as important components that may have led to improved outcomes. A 'therapeutic relationship' has often been used synonymously with relational continuity of care in primary care settings^{13, 84}, although continuity of care was not specifically defined in this trial.

A retrospective analysis of administrative data from primary care clinics in the USA, in a study examining the effects of increased primary care access on depression care, found that an improvement in antidepressant medication use was associated with improved continuity of care⁴⁹.

A cross-sectional analysis of data collected after a depression quality improvement intervention had taken place in primary care clinics in the USA found that higher ratings of the interpersonal relationship with the primary care provider were associated with better adherence with medication for depression⁷².

Palliative Care: GPs not only play a significant role in the delivery of palliative care to patients who are dying but also act as co-ordinators of care across organisations and as key gatekeepers to palliative care. However, a limited literature exists on continuity of care and palliative care with relevance to general practice. For example, one systematic review evaluating palliative care delivered by GPs⁸⁵ and three studies were identified: a retrospective audit study examining the issue of the transfer of information (informational continuity) between GPs and out-of-hours provision⁸⁶, an action research study on patient views about effective cancer care in primary care⁸⁷ and a qualitative study exploring the value of palliative care in primary care, including continuity of care⁸⁸. However, no literature was identified examining the relationship between continuity of care and palliative care in relation to patient outcomes such as patient satisfaction, quality of life or mental health issues relevant to end of life care.

Summary

Empirical evidence suggests that continuity of care can influence the quality of medical care in relation to some processes of care. However, evidence to support the value of improved continuity of care in terms of improved patient outcomes is equivocal. The main problem with this body of research is that the definition of continuity of care differs across studies and is often poorly defined or inadequately measured. Furthermore, evaluating the impact of continuity of care on patient outcomes is challenging due to the contribution of multiple factors to health care outcomes⁸⁹. Studies examining the link between continuity of care and patient outcomes have seldom investigated patient variables that have the potential to influence patient health outcomes. Failure to address these methodological limitations may affect the ability of studies to detect any potential benefits of continuity of care.

Despite the potential benefits of continuity of care, however, many questions have been raised regarding the importance to patients of different aspects of continuity of care and why it matters. The following section represents a summary of studies reporting patients' views on aspects of continuity of care.

Table 1. Characteristics of reviews focusing on the relationship between continuity of care and patient outcomes

Reference	Study designs	Study focus	Population focus
Cabana and Jee 2004 ¹⁷	RCT, Cohort, Cross-Sectional	Process of care, clinical outcomes and cost of care	All patient populations
Saultz and Albedaiwi 2004 ¹⁸	RCT, Cohort, Correlation	Patient satisfaction	All patient populations
Saultz and Lochner 2005 ¹⁹	RCT, Cohort, Correlation, Case Control	Process of care, clinical outcomes and cost of care	All patient populations
Freeman 1984 ²²	All study designs	Continuity of care in general practice	All patient populations
Worrall and Knight 2006 ²¹	RCT, Observational	Chronic Disease and clinical outcomes	Elderly patients
O'Malley 2004 ⁵⁴	All study designs	Process of care, clinical outcomes and cost of care	Children and adolescent patients

Table 2: Empirical studies on continuity of care (COC) and outcome (1992-2007)

Study Reference	Design	Population/Setting	Outcome	Operationalization of continuity	Results
Kelly and Shank 1992 ⁶¹	Cross-sectional	Adult patients aged 50+ in family practices	Adherence to physician recommended screening	COC calculated from median values for number of years in practice or number of visits to assigned physician	COC linked to better adherence to colorectal cancer screening
Freeman and Richards 1994 ⁷⁶	Cross-sectional	Primary care patients aged 15-64 with epilepsy, UK	Discussion with doctor	Patient response to three questions and Usual Provider Continuity Index (UPCI).	COC not associated with discussion of epilepsy but associated with ease of talking to doctor
Flocke et al 1998 ⁵⁷	Cross-sectional	Adult patients/community-based primary care physicians, USA	Receipt of preventive services (screening, health habit counselling, immunization)	Components of Primary Care Instrument (CPCI); patient preference to see usual physician	COC associated with receipt of clinical preventive services
Meredith et al 2001 ⁷²	Cross-sectional	Adult patients with depression, USA	Patient satisfaction; quality of care	Components of CPCI	Interpersonal relationship and patient satisfaction positively associated with quality care for depression
Cree et al 2002 ⁷⁴	Prospective cohort	Adult patients (age 65+), Canada	Decline in health	COC assessed by sequential continuity using SECON – measures tendency to visit the same physician	Low COC associated with hospitalisation and hip fracture; high COC less common among hip fracture patients
Khunti et al 2002 ⁷⁵	Cross-sectional	Adult general practice patients with coronary heart disease, UK	Quality of care	Percentage of consultations out of the past 12 with most frequently consulted doctor	Increased COC not associated with improved clinical care
Parchman et al 2002 ⁴⁸	Cross-sectional	Adult family practice patients, USA	Quality of care	Questions adapted from the Components of Primary Care Instrument (visit based calculation of COC score)	Significant association between COC and quality of care
Broom 2003 ⁶⁹	Qualitative	Adults with type 2 diabetes, Australia	Early detection of diabetes	Discontinuity defined as: diagnosis made by someone other than regular GP	Two-thirds received diagnosis as a result of discontinuity
Gill et al 2003 ⁶⁸	Cross-sectional	Adults with diabetes mellitus, USA	Diabetes monitoring (glycosylated haemoglobin test, lipid profile, eye exam)	Provider continuity of care by Modified Modified Continuity Index (MMCI)	No association between COC and diabetes monitoring
Koopman et al 2003 ⁷¹ Mainous et al 2004 ⁹⁰ (reporting same study)	Secondary analysis of household survey	Adults with common chronic diseases, USA	Proportion of unrecognised disease (diabetes, hypertension, hypercholesterolemia)	Patient response to 1.usual source of care; 2.usual provider of care	Patients with usual provider were less likely to have unrecognised diabetes. Continuity not a predictor of unrecognised hypertension or hypercholesterolemia
Pereira et al 2003 ⁶²	Quasi-experimental	Adult patients, USA	Preventive screening; control of diabetes and hypertension; utilization of urgent care or ED visits	Quality of care comparison between departing and remaining physicians	No decrease in quality of care associated with discontinuity of care
Sherina et al 2003 ⁶⁶	Cross-sectional	Adult patients with diabetes, Malaysia	Diabetic control (HbA _{1c})	Usual Provider Continuity Index (UPCI)	No relation between COC and diabetic control
Doescher et al 2004 ⁵⁸	Cross-sectional	Adult patients, USA	Preventive services (influenza vaccination; mammography; smoking cessation advice)	Categorical: patient identification of regular provider and site continuity	Provider and site continuity independently associated with receipt of preventive services

Kerse et al 2004 ⁷⁷	Cross-sectional	Adult general practice patients, New Zealand	Medication compliance	Patient report on duration and importance of seeing own doctor/calculation of Usual Provider Continuity Index (proportion of consultations with usual physician)	COC not related to compliance with medication
Mainous et al 2004 ⁶⁰	Cross-sectional	Adult patients with newly diagnosed breast and colorectal cancer, USA	Preventive screening visits one year prior to diagnosis; trust in physician	Patient self-report; duration of continuity; Usual Provider Continuity score	COC prior to diagnosis related to receipt of mammography; COC not related to earlier detection of cancer
Donahue et al 2005 ⁶³	Cross-sectional	National survey of adult rural patients, USA	Patient satisfaction; preventive services	Patient response to 1.usual source of care; 2.usual provider of care	Positive relationship between COC and patient satisfaction; no association between continuity of care and preventive services
Fan et al 2005 ⁷³	Cross-sectional	Adult primary care patients, USA	Patient satisfaction	Patient self report, how often same doctor seen on visits	COC strongly associated with greater patient satisfaction
Litaker et al 2005 ⁶⁷	Retrospective cohort	Adult patients with diabetes, USA	Cardiovascular risk factor management	Visit pattern assessment based on complete continuity with a single clinician vs. multiple clinicians	No association between COC and patient attainment of goals for cardiovascular disease risk factor control
Menec et al 2005 ⁵⁹	Cross-sectional	National survey of adult patients, Canada	Preventive health care	COC defined as more than 75% of total visits to family physicians	COC related to better preventive health care and reduced ED use
Reid et al 2005 ⁶⁵	Observational study set within a randomised controlled trial	Adult and adolescent primary care patients, USA	Preventive screening (chlamydia testing)	Calculation of usual Provider Continuity Index (proportion of primary care visits with usual physician) and Continuity of Care Index (accounts for different providers seen)	Inverse relationship between COC and chlamydia testing
Cyr et al. 2006 ⁷⁸	Retrospective cohort	Adolescents with asthma, Canada	Emergency department (ED) visits; Hospitalisations for asthma	RxICC and COC (continuity indexes)	No significant association between COC, hospitalisations and ED visits
Drivsholm and Olivarius 2006 ⁷⁰	Cross-sectional	Adult patients with newly diagnosed diabetes, Denmark	Glycosylated haemoglobin A _{1c}	GP reported duration of patient registration at practice and how well they knew patients	Less well known patients presented with high glycaemic levels at diabetes diagnosis
Gulliford et al 2006 ¹⁴	Longitudinal cohort	Adult patients with type 2 diabetes, UK	Patient satisfaction; diabetic control (HbA _{1c})	The Experienced COC measure	COC associated with patient satisfaction; COC not associated with diabetic control
Hunkeler et al 2006 ⁸³	Two-arm randomised clinical trial	Primary care patients aged 60+ with major depression, USA	Depression; functional impairment; quality of life; physical function; depression treatment; patient satisfaction	COC not assessed	Improvement in outcomes applicable to patients assigned to collaborative care management arm of trial
Menec et al 2006 ⁵⁵	Cross-sectional	Older adult patients, Canada	Hospitalisations for ambulatory care-sensitive medical conditions	Continuity of care derived from billing data, using a majority of care definition	High COC associated with reduced odds of ambulatory care-sensitive hospitalisations
Solberg et al 2006 ⁴⁹	Retrospective cohort	Adults with depression, USA	Process measures	COC defined as more than 50% of visits are with one primary care clinician	COC associated with antidepressant continuation

Mathews and Park 2007 ⁶⁴	Cross-sectional	National survey of adult patients, Canada	Self-reported health status; preventive care; patient satisfaction	COC assessed using dichotomous responses to one question	No relationship between CoC and health related outcomes
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Objective 4: summarise patients' views of CoC and, in particular, to provide a summary of the evidence base on patients for whom CoC within primary care is of most and least importance.

Patients' Views on Continuity of Care

There is still debate about whether some patients value interpersonal continuity within primary care more than others and on issues surrounding competing features of health care system level factors, such as rapid access and continuity.

Patients' conceptualisation of continuity of care

Studies using either focus groups or interviews with open-ended questions to explore patient perceptions on the meaning of continuity of care found that patients' perceptions of continuity of care were similar to continuity of care dimensions identified in the conceptual literature^{10, 11}. For example, in one study of patients with diabetes in Canada¹⁰) and one study of patients with diabetes in the UK¹¹ patients valued timely access to clinical services in response to changing needs (flexible continuity), an ongoing relationship with the same care provider who knows the patient's medical and personal history (relational and longitudinal continuity) and co-ordination of care across professionals at the same and other locations (team and cross-boundary continuity). In addition, patients in Canada identified personal responsibility for managing their condition as an important aspect in maintaining effective continuity of care, which also involved being assertive about obtaining information and making and keeping appointments¹⁰. This aspect of continuity has not traditionally been included in current conceptualisations of continuity of care and the authors suggested that this omission might account for contradictory findings in the literature. Another patient-derived dimension of continuity was identified from a qualitative study examining how primary care patients perceive interpersonal continuity of care⁹¹. Patients identified 'comfort with a doctor' as an important element of establishing and maintaining an ongoing relationship with primary care physicians.

Synthesis of Systematic Reviews on Patients' Views of Continuity Of Care

Characteristics of Systematic Reviews

One narrative review was identified that focused on examining patients' perceptions of interpersonal continuity of care across practice settings, including primary care⁹². The authors identified 36 relevant articles from a search of two databases (ISI Web of Knowledge and Medline, from 1966 through 2005). Quality assessment of this review revealed that research questions were reported, the search term used was limited to 'continuity of care', specific inclusion or exclusion criteria were not reported, and two authors independently selected the studies for inclusion but did not report on how disagreements were resolved. Assessment of the validity of the included studies was not reported nor were sufficient details provided for each article; the authors reported on the findings only. The narrative synthesis of results was appropriate given the heterogeneity of the reviewed studies. Full text articles were therefore obtained and reviewed to provide additional descriptive information.

Results

Methods used by studies: From a review of the primary studies identified in the medical literature (see Table 3), a variety of research methods have been used to determine patients' views of continuity of care and the individual differences in preferences for continuity of care. The difference in approaches inevitably reflects the different questions asked by the researchers. However, in most studies, the researchers rather than the patients have chosen the items thought to be important. Therefore, what is meaningful or relevant to patients may

not be reflected in their responses. Focus groups avoid this pitfall, but present a challenge in analysing individual differences or values.

Other qualitative approaches used in the literature, such as semi-structured interviews, are useful for determining patients' perceptions of the value of continuity of care as well as providing the reasons underlying their choices, but less useful in terms of providing information on measurable relationships between responses relating to patient values and other variables of interest. This drawback of unstructured interviews is precisely the advantage of survey methods; and several studies using this approach also used ratings and rankings to prioritise various aspects of general practice care. However, this method relies on the use of valid measures of continuity of care and other aspects under investigation.

Patients may also rate all features of care as "extremely important" but have not been given an opportunity to evaluate trade-offs with other aspects of care. A solution to this methodological problem in exploring preferences and trade-offs is the use of utility-based methods such as conjoint analysis, but this survey-based technique has seldom been used in determining patient preferences for different aspects of primary care in relation to continuity of care. Conjoint analysis (discrete choice experiments) is useful in eliciting individual preferences and trade-offs, allowing utilities to be estimated for specific attributes of health care and thus an approach useful for measuring the relative value of competing health care services or choices⁹³. One study was found that used this methodology to investigate patient preferences and trade-offs between different aspects of care¹⁶.

Sample size and sampling procedures were varied across studies. Sample sizes ranged from 13⁹⁴ in a focus group study to 19,913⁹⁵ in a cross-sectional survey, and the majority of studies used either a self-selected or convenience sampling procedure.

Is continuity of care valued by patients?

Pandhi and Saultz⁹² described the findings of patients' perceptions of interpersonal and longitudinal continuity in various healthcare settings, including general practice. They found that interpersonal continuity was considered to be important to most patients who valued the relational aspects with a personal physician, including the personal knowledge physicians have about them and the ease which they felt they could communicate their concerns to their personal physician. The main recommendations were: future research is needed to improve understanding of the benefits patients perceive about having a doctor who has knowledge about them, medical consequences of not receiving continuity of care when desired, and patients' preferences for continuity of care should be considered when structuring the delivery of care.

Full-text articles were retrieved that reported on research that specifically focused on exploring patient views on the value of interpersonal continuity. The findings of these studies consistently indicate that a majority of patients particularly value interpersonal, informational and longitudinal continuity. For instance, in the UK studies it was found that a continuing relationship was central to personal care or for perceived quality of care, and many patients reported wanting to see the same GP "a lot of the time" or valued highly having a personal doctor^{7, 16, 84, 96-103}. In one UK cross-sectional survey of primary care patients' preferences, 65.2% of patients placed importance on being able to consult a particular person and consulting someone known and trusted was important to 62.6% of patients¹⁰³. In another UK study, using in-depth semi-structured interviews, patients diagnosed with diabetes valued four dimensions of continuity of care as important: longitudinal continuity, relational continuity, flexible continuity and team and cross-boundary continuity¹¹.

These results are supported by the findings of the American and Canadian studies, which found that a majority of patients preferred to consult their regular doctor or valued the doctor-

patient relationship^{9, 99, 104-107}. The percentages of patients expressing these views ranged from 37.4%¹⁰⁵ to 92.4%⁹⁹.

Similar findings have been reported in the international literature. For instance, in a cross-sectional survey study, conducted in Malaysia, 89% of patients diagnosed with diabetes reported that they felt it was important to have a regular doctor⁶⁶. In a recent study of non-registered private patients attending primary health care facilities in Ireland, 82% of respondents expressed a preference for seeing a regular GP¹⁰⁸. Findings from an international comparison study conducted in Europe and Israel, in which patients were asked to indicate the relative importance of 40 aspects of care, suggest that seeing the same GP at each visit was given a higher priority rating in Norway (ranked 6) and Sweden (ranked 9) than in the UK (ranked 28)¹⁰⁹. In another study comparing USA and UK general practice patients, US patients were more likely to value continuity than UK patients, 92.4% versus 70.8% respectively⁹⁹. This however may reflect differences in health care systems.

Which patients most value continuity of care?

Pandhi and Saultz⁹² found that continuity of care was of particular importance to certain patient groups the authors defined as 'vulnerable'. Those groups included parents with young children, elderly patients, less wealthy and less educated patients and patients with chronic conditions.

Several studies have explored how patients with different health problems value continuity of care or have investigated the influence of patient-related characteristics, such as age, gender and socio-economic status, on views on continuity of care. As far as patient-related characteristics are concerned, results are mixed. Continuity appears to be valued more by older patients^{95, 97, 110}, middle-class patients⁹⁴ and females^{9, 110, 111}. However three studies based in The Netherlands¹¹², UK⁹⁷ and US⁹ was unable to establish a significant relation between preference for seeing a personal GP and patient age or gender.

Two qualitative studies, one conducted in the USA and one in Australia, investigated differences in patients' views on aspects of continuity of care as a function of socio-economic background. Findings of these studies indicated that patients from lower socio-economic backgrounds expressed equal value on accessibility and the physician-patient relationship in the USA¹⁰⁵ or emphasise aspects of care related to flexible and informational continuity compared to middle-class patients who emphasise provider continuity in accounts of experienced continuity of care in Australia⁹⁴. Similar findings come from a study conducted in Switzerland in which socio-economic differences were found¹¹³. Patients of lower socio-economic status emphasised the importance of convenience and access factors whereas patients of higher socio-economic status emphasised the importance of the physician-patient relationship and interpersonal continuity.

People with enduring mental health problems also value continuity of care. In a qualitative study of primary care patients with enduring mental health problems¹⁰¹, patients emphasised the importance of building a continuing relationship with one person over time. Informational continuity was also important to these patients in order to avoid having to repeat personal histories to different health professionals. Interpersonal and longitudinal continuity were dimensions of continuity also reported to be essential for good quality of primary care for people with serious mental illness in another qualitative study of primary care patients⁹⁸.

Studies assessing patient preferences

Pandhi and Saultz⁹² reported on the findings of studies that measured the strength of patient preference for interpersonal continuity of care. They found five studies in which patients reported their willingness to wait longer to see their personal physician. Their results

suggested that more than half of the patients surveyed in one of the included studies were willing to pay a small monthly fee to maintain continuity with their physician, and patients with chronic conditions were more likely to sacrifice extra money for continuity.

The study using the willingness to pay (WTP) approach, with monetary and time sacrifices as indicators of the value of continuity of care, also found that poor and less educated patients were less likely to pay extra money to maintain continuity but were more likely to drive more than an hour to maintain continuity of care, as were patients older than 50 years⁹. The authors concluded that willingness to pay provides a more sensitive method of measuring perceived value of continuity compared to patients' attitudes toward continuity of care. Although the WTP approach has an advantage of conveying strength of patient preferences, this method, however, is restricted by the participant's budget, which will obviously vary across income groups. Failing to adjust for income differences in studies eliciting strength of preference for different aspects of primary care using the WTP method might produce misleading results; wealthier patients will be able to express a greater WTP. This may be reflected in the results of the study in which the less wealthy, less educated and older patients were more likely to express their value of continuity in terms of time rather than money.

When and why do patients value continuity of care?

Pandhi and Saultz⁹² reported on studies that focused on exploring which patient groups continuity of care was more important to and the reasons why. The results of empirical studies suggest that interpersonal and informational continuity of care are most valued in certain situations and for particular medical conditions such as serious or chronic illnesses, including mental illness. Interpersonal continuity is especially valued by patients requiring more medications¹¹⁰, patients receiving of end-of-life care^{88 112}, patients with complex medical conditions^{7, 114} or consulting with emotional concerns, psychological problems or family issues^{7, 9, 84, 114}, but undesirable for discussion of embarrassing conditions. Interpersonal continuity was also less important to patients who perceived themselves as busy or those who led 'chaotic' (not defined in the paper) lives⁷.

In a UK study, eliciting patient preferences using hypothetical clinical cameos, having a personal GP was rated as 'very important' by patients to serious medical conditions but for minor illness it was valued much less⁸⁴. In a mixed methods study conducted in the USA, the majority (73%) of female patients enrolled in a health maintenance organisation indicated the importance of seeing the same doctor for every visit¹¹¹. However, patient preference varied depending on the type of health problem presented. When asked to consider the importance of seeing their regular doctor or a different doctor for an acute visit, such as flu or a sore throat, 72% of women were comfortable seeing another doctor but 65% expressed a preference for a regular doctor for routine checkups.

In a qualitative study using in-depth interviews⁷ all patients were unanimous about the circumstances in which a continuing relationship was important. When the consultation involved an acute problem that could be resolved easily, most patients did not prioritise interpersonal care over seeing an unfamiliar health professional. However, in circumstances where there were competing priorities, a long-term relationship was considered essential when long-term problems, complex problems or emotional problems were the reasons for consultation, with patients preferring relational continuity over the convenience of seeing an unfamiliar health professional.

In a study employing in-depth interviews, 13 out of 14 patients in Swedish primary health care centres with long-term chronic illnesses (e.g., diabetes, rheumatoid arthritis, coronary heart disease, depression and lower back pain) preferred to consult a personal doctor¹¹⁶. In a further qualitative study, which examined patients' experiences and values related to

continuity in diabetes care, patients reported that seeing a personal doctor gave them a “sense of security”¹¹. This was related to the perception that an ongoing relationship allowed more knowledge of the patient’s medical history and consequently, through familiarity, changes in health status would more likely be noticed. In particular, seeing a usual provider was important during the early months after diagnosis of diabetes, especially when experiencing complications or having difficulty accepting or managing the condition. Patients with a diagnosis of cancer identified continuity of care as an issue of concern and considered it to be central to good cancer care⁸⁷. Secondary analysis of data from a telephone survey of adults in the use of health care in the USA revealed between group differences in how long they would wait to see their own doctor for acute, non-life-threatening illness before seeking care elsewhere¹¹⁵. Multivariate analysis revealed that older and non-white patients were more likely to seek same day alternate care.

Pandhi and Saultz⁹² identified a number of studies that examined the reasons why patients value interpersonal and longitudinal continuity of care. They reported that patients valued the doctor-patient relationship, physician knowledge of the patient, good communication skills, and trust and confidence built up over time.

Studies using the method of open-ended questions or in-depth interviews, however, do not give an indication of the relative importance of the features of care to patients. Studies using an approach based on quantitative methods are needed to elicit preferences or priorities, such as surveys or consensus methods using ratings or ranking and other techniques including conjoint analysis methods such as discrete choice experiments¹⁶ or willingness to pay to express patient values⁹.

When do patients make trade-offs between different aspects of care?

Although several studies have found that patients do value seeing the same doctor, the more interesting questions relate to patient preferences when faced with competing health care priorities. Having a ‘regular doctor’ does not guarantee continuity of care, as patients may choose to seek care from another doctor in particular circumstances. Few studies have focused on this issue by exploring preferences for care and factors related to patients’ decisions to seek care from alternative health care systems or health care providers. In the literature only one study was found in which the preferences of patients were explored by addressing the relative importance of aspects of primary care to increase understanding of the circumstances in which patients might trade off continuity of care for other aspects of service delivery, such as speed of access¹⁶.

A NHS, SDO Research and Development Programme commissioned study explored the views of patients on the relative importance of continuity of care and other aspects of primary care, using a preference discrete choice experiment as a technique to elicit patient preferences¹⁶. This methodology involved asking patients to choose between pairs of hypothetical scenarios that differed in terms of a relevant attribute of a primary care consultation. Relational continuity, informational continuity, type of health professional, and access were chosen as attributes. The number of ‘options’ or ‘levels’ of each attribute differed, ranging from two to four. For example, the levels of one of the attributes were chosen to reflect doctor led care or nurse led care. The patient is presented with a scenario and asked to indicate their preference, and all other scenarios are compared with it.

The results indicate that patients prefer to see a GP, to see someone they know, to see someone who has access to their notes, and prefer shorter wait times. Results of this study are consistent with other work^{7, 84, 111, 115} in that they demonstrate that continuity of care is of lesser priority to patients with minor, acute problems than quick access to care. However, individuals in poorer health valued continuity more and preferred to wait longer to receive continuity. The results also indicate that continuity of care was valued more highly by patients

with more complex health problems and by patients attending routine consultations for chronic conditions. Also, there were individual differences in preference for seeing a GP rather than a nurse. Non-white, better-educated and retired patients and frequent attendees had stronger preferences for seeing a GP rather than a nurse.

Results from GPAQ and the 2007 'Your Doctor, Your Say' Access survey

The National Primary Care Research and Development Centre holds two sets of survey data relevant to the current debate on GP access. Unpublished data from the GPAQ survey data for random samples of patients from the 42 QUIP practices over three time periods shows the following results:

	1998 Percentage reporting 'good, very good, or excellent' n=3221	2003 Percentage reporting 'good, very good, or excellent' n=3816	2005 Percentage reporting 'good, very good, or excellent' n=4327
How do you rate the hours your practice is open for appointments?	75%	78%	78%
How do you rate how quickly you get an appointment with a particular doctor	45%	51%	56%
How do you rate how quickly you get an appointment with any doctor	61%	67%	70%

Patients' rating of access improved between 1998 and 2003, and again between 2003 and 2005. Data from the 2006 'Your Doctor, Your Say' access survey suggests that there has been further improvement between 2005 and 2006. Responses to the access survey were received from 2,295,987 people. In summary:

86 per cent of people reported that they were satisfied with their ability to get through to their doctor's surgery on the phone

86 per cent of people who tried to get a quick appointment with a GP said they were able to do so within 48 hours

75 per cent of people who wanted to book ahead for an appointment with a doctor reported that they were able to do so

88 per cent of people who wanted an appointment with a particular doctor at their GP surgery thought they could do this

However, there is a minority (9% to see 'any doctor', 15% to see 'a particular doctor') who rated access as 'poor' or 'very poor'.

A question was raised within the access survey whether any particular population group experienced worse access. NPCRDC GPAQ survey data from the 2005/06 contract year found no evidence of substantial inequality in actual waiting times between ethnic minority groups. Overall, 86% of patients are able to see a GP within two days.

	White	Black or Black British	Asian or Asian British	Other	Total

Percentage usually able to see 'a particular GP' within 2 days	60%	67% ^a	66% ^a	63%	60%
Percentage usually able to see 'any GP' within 2 days	86%	82% ^b	81% ^b	82% ^b	86%

More than 6000 respondents in each of the ethnic minority groups

^a Significantly higher than the white population, controlled for age, socio-demographic factors and health status

^b Significantly lower than the white population, controlled for age, socio-demographic factors and health status

Summary

Several qualitative and cross-sectional preference survey studies have explored patients' views about continuity of care and investigated whether patients would trade access to care for interpersonal continuity of care as a way to express their preference for seeing the same doctor. Patients do value seeing the same doctor, but other factors, such as the nature of their illness and ease of access to care, may take priority. For minor problems, continuity of care is less important.

Patient preferences elicited using a discrete choice experiment and a study using a willingness to pay method have demonstrated patient characteristics to be an important determinant of the value of continuity of care. Health status, age, economic status, ethnicity and education affected preference for continuity of care. Although the results suggest that there is variation in the importance placed on continuity of care as a consequence of some patient characteristics explanations for these differences are usually not incorporated in most studies. Therefore, possible explanations beyond patient characteristics such as the health care system they operate in are not easy to determine. Although there is a large body of work on ethnic inequalities in the primary care experiences of adults and children (see Stevens and Shi¹¹⁷ for a review of this literature), this topic has yet to be considered in the continuity of care research field.

There is a lack of agreement on how to measure continuity of care and few simple and only two validated tools to measure it (both in diabetes care),^{39, 118} particularly from the patient perspective.

Table 3. Studies on patient views on continuity of care

Author (Reference number)	Setting	Sample size/ response rate	Design	Methods	Aim of study
Tarrant et al, 2003 ⁷	UK, 6 general practices	40 adult patients (response rate not reported)	Qualitative	In-depth interviews, open-ended questions/ purposive sampling	Patients' perceptions of the features of personal care
Pereira & Pearson, 2003 ⁹	USA, health maintenance	1171 adult patients (46.8%)	Cross-sectional	Survey-based: postal questionnaire	Patient attitudes and preference toward continuity of care with a primary care

Author (Reference number)	Setting	Sample size/ response rate	Design	Methods	Aim of study
	organisation			e/willingness to pay/random sample	physician
Nair et al, 2005 ¹⁰	Canada, health service organisation	46 adult patients with diabetes sampled from 404 patients enrolled in larger study	Qualitative	Focus group interviews/ purposive sampling	Meaning of continuity of care from the perspective of patients with diabetes
Naithani et al, 2006 ¹¹	UK, 14 general practices	25 adult patients with type 2 diabetes (83%)	Qualitative	In-depth semi-structured interviews/ purposive sampling	Patients' experiences and values on continuity of care
Baker et al, 2001 ¹⁶	UK, general practices	79 adult patients; subset 36 adult patients. 1437 patients (46.5%)	Multi-methods	In-depth semi-structured interviews; analysis of consultation record and practice notes; postal questionnaires/random sample	To determine patient views on the relative importance of continuity compared to other aspects of care
Kendall et al, 2006 ⁸⁷	Scotland,	18 adult patients	Qualitative	Focus group interviews/ purposive sampling	How primary care can best support patients with cancer
Borgsteede et al, 2006 ⁸⁸	The Netherlands, primary care	20 GPs and 30 adult patients (response rate not reported)	Qualitative	In-depth semi-structured interviews/convenience sampling	Perspectives on good end-of-life care
Pandhi et al, 2007 ⁹¹	USA, primary care	14 adult patients	Qualitative	In-depth semi-structured interviews/ random & purposive sample	Patients perceptions of interpersonal continuity
Liaw et al, 1992 ⁹⁴	Australia, 2 primary	13 adult patients	Qualitative	Focus group interviews/2	Patient perceptions of continuity of care

Author (Reference number)	Setting	Sample size/ response rate	Design	Methods	Aim of study
	medical care facilities	(13.5%)		-item postal questionnaire/ random selection	and comparison of socio-economic differences
Guthrie, 2002 ⁹⁵	UK, 53 general practices in four regions	19,913 adult patients (76.6%)	Cross-sectional	Survey-based: pre and post-consultation self-report questionnaire/ consecutive sample	Practice and patient factors associated with personal continuity of care
Bower et al, 2003 ⁹⁶	UK, general practices	14,291 Adult patients (response rate not reported)	Cross-sectional	Survey-based: self-report and postal questionnaire/ random sample (secondary analysis of data)	Patients' views on access and continuity in general practice
Freeman & Richards, 1993 ⁹⁷	UK, 3 group practices	111 adult patients (87%)	Cross-sectional	Survey-based: semi-structured interviews and continuity index measure/ random selection	Patients' value of continuity of care
Kearley et al, 2001 ⁸⁴	UK, 18 general practices	996 adult patients (55%)	Cross-sectional	Survey-based: postal questionnaire/ random selection	Perceived value of having a personal GP, perceived value of convenience and to establish relative importance of these aspects
Lester et al, 2005 ⁹⁸	UK, 6 primary care trusts	45 adult patients with serious mental illness (response rate not reported)	Qualitative	Focus group interviews/ purposive sampling	Patients' views on primary care
Mainous et	USA	418 US and	Cross-	Survey-	Relationship

Author (Reference number)	Setting	Sample size/ response rate	Design	Methods	Aim of study
al, 2001 ⁹⁹	ambulatory and UK general practices	650 UK adult patients (response rate not reported)	sectional	based: self-report questionnaire/ consecutive sample	between continuity of care and trust in the physician
Mercer et al, 2007 ¹⁰⁰	UK, primary care organisation	72 adult patients (response rate not reported)	Qualitative	Focus group interviews/convenience sampling	Patients' views on quality of care
Kai & Crosland, 2001 ¹⁰¹	UK, 4 general practices	32 adult patients	Qualitative	In-depth semi-structured interviews/theoretical sampling and purposive sampling	Experiences and perceptions of health care of people with enduring mental ill health
Baker et al, 2007 ¹⁰³	UK, 22 general practices and walk-in centre	1,437 adult patients (46.5%)	Cross-sectional	Survey-based: postal questionnaire/ random sample	Patient preferences for continuity of care
Lewis et al, 2000 ¹⁰⁴	USA, Internal medicine practices (hospital based clinics)	314 adult patients	Cross-sectional	Survey-based: telephone survey/random sample	Patients' preferences for care for common medical conditions
O'Malley et al, 2000 ¹⁰⁵	USA, 4 community health clinics	24 adult female patients (response rate not reported)	Qualitative	Focus group interviews/self selected sample	Low-income women's priorities for primary care
Roberge et al, 2001 ¹⁰⁶	Montreal, Primary care practices	23 adult patients	Qualitative	Focus group interviews	Patient views on loyalty to regular care provider
Mathews & Barnsley, 2003 ¹⁰⁷	Canada, households	785 adult patients (72%), reports on 304 patients with acute illnesses	Cross-sectional	Population-based telephone survey/random selection	Factors predictive of patient preference for seeing their regular doctor

Author (Reference number)	Setting	Sample size/ response rate	Design	Methods	Aim of study
Sherina et al, 2003 ⁶⁶	Malaysia, family practice clinic	166 adult patients with type 2 diabetes (100%)	Cross-sectional	Survey-based: structured interview and continuity index measure/ consecutive sample	Importance of continuity of care among patients with diabetes
Carmody & Whitford, 2007 ¹⁰⁸	Ireland, population-based	400 adult patients (56.2%)	Cross-sectional	Survey-based: telephone survey/ random sample	Attitudes of private GP patients towards continuity of care
Grol et al, 1999 ¹⁰⁹	International study (UK, Norway, Sweden, Denmark, The Netherlands, Germany, Portugal and Israel), general practices	3,540 adult patients (55%)	Cross-sectional	Survey-based: postal questionnaire/ consecutive sample	Priorities of patients in general practice care
Nutting et al, 2003 ¹¹⁰	USA, 84 family practices	2,763 parents of children and adult patients (61%)	Cross-sectional	Multimethod study using questionnaires, medical records, continuity index measure/ consecutive sample	Patient value of continuity of care and associated patient and visit characteristics
Thompson & Nussbaum (2000) ¹¹¹	USA, Health Maintenance Organization	500 female patients	Multi-methods	Survey-based: telephone interviews; focus groups and in-person interviews	Women's flexibility about seeing an unfamiliar physician and identify characteristics associated with preference flexibility
Schers et al,	The	644 adult	Cross-	Survey-	Patients' views on

Author (Reference number)	Setting	Sample size/ response rate	Design	Methods	Aim of study
2002 ¹¹²	Netherlands, 35 general practices	patients (74%)	sectional	based: postal questionnaire/ consecutive sample	continuity of care in general practice
Guthrie & Wyke, 2006 ¹¹⁴	Scotland, 10 general practices	32 adult patients (74%)	Qualitative	In-depth semi-structured interviews/ purposive sampling	Value of continuity of care to patients
Love 1999 ¹¹⁵	USA, General population	658 adult patients (39%)	Quantitative	Survey-based: telephone survey/ random sample	Factors related to patients' decision to seek care for acute illness from someone other than regular physician
Von Bültzingslöwen et al, 2006 ¹¹⁶	Sweden, 3 primary health care centres	14 chronically ill patients (response rate not reported)	Qualitative	In-depth interviews, open-ended questions/ purposive sampling	Value of continuity of care to patients
Alazri et al, 2006 ¹⁰²	UK, 7 general practices	79 adult patients with type 2 diabetes (response rate not reported)	Qualitative	Focus group interviews/ purposive sampling	Patients' views on advantages and disadvantages of continuity of care

Objective 5: Summary of the methods of measuring different aspects of continuity of care from a UK and international perspective.

Synthesis of Systematic Reviews on Continuity Of Care Measures

Characteristics of Systematic Reviews

Four reviews were identified that considered how continuity had been defined and measured in the healthcare literature^{20, 23, 24, 35}. These reviews focused on describing and evaluating individual-based measures^{20, 35} and disease-specific measures^{23, 24}. Over the past three decades a large number of indices and tools have been developed to measure continuity of care. Many of the instruments are unidimensional measures of continuity of care that attempt to capture the concept in a single global measure, whereas other measures have been developed within a multidimensional conceptual framework and are useful as patient-based measures.

All reviews reported the purpose of the review; stated inclusion and exclusion criteria used to select articles, described the search strategy and reported the timeframe covered by the search. Each review specified the databases searched, ranging from one database searched (Medline)³⁵ to eight databases used²³. Data abstraction was undertaken by at least two independent reviewers in all but one of the reviews that was conducted independently³⁵. In the reviews undertaken by more than one study team member, only one review reported on the method for resolving disagreements between reviewers and this was achieved by informal consensus and a kappa score calculated²⁰. All the reviews provided sufficient details of included studies and summarised the studies appropriately.

Results

Content of Measures: Most reviewers arrived at the same conclusion that the content of instruments varies substantially. The diversity of definitions of continuity of care contributes to the complexity of the choice researchers face in selecting an appropriate measure. Many of the measures examine a single aspect of continuity, commonly provider continuity, with a focus on longitudinal or chronological aspects of care; with most measuring the proportions and ratios of visits to the same health care professional or usual provider. These measures have been criticised as measuring the health system attributes that may be needed to achieve continuity without measuring the construct of continuity¹³. For example, the proportion of consultations with a single doctor is really a measure of 'access' or 'utilization of services'. It may help to achieve managerial or interpersonal continuity but numerical measurement of visits does not indicate if either dimension of continuity was actually achieved or provide evidence of the strength of the doctor-patient relationship.

Another major issue is that instruments have been developed within specific healthcare domains such as continuity of care in diabetes^{39, 118}. Disease-specific measures are most appropriate when studying relevant patient groups. In all of the reviews, concerns about the validity of instruments are commonly expressed. Table 4 summarises the approaches to measuring continuity from the patient's perspective for use in primary care settings.

Chronological Measures: The growing interest in measuring continuity of care is reflected in a systematic review of the literature reporting on the application of numerous different continuity of care indices in primary care related studies²⁰. These authors searched English-language articles using MEDLINE, ERIC and PsycINFO electronic databases from 1966 to 2002, resulting in 246 candidate articles relevant to primary care. Jee and Cabana²⁰ identified 44 articles, of which 32 involved different indices used to measure continuity of care. Continuity of care was more often assessed using density measures (n = 17), followed by dispersion measures (n = 8), subjective/miscellaneous measures (n = 4), duration

measures (n = 2) and sequence measures (n = 1). The authors provided a description of the five methods of assessing continuity of care as:

Duration: measures length of time with a particular provider

Density: characterises visits with the same doctor quantified by number or percentage of visits over a defined time period

Dispersion: quantifies the number or percentage of visits with distinct providers

Sequence: accounts for the order in which different providers are seen.

The authors concluded that there is a lack of consensus between studies examining continuity of care about its operational definition and its measurement, and no index included all components of continuity of care. Other problems involve the complexity of calculation required to quantify continuity and difficulties in interpretation.

In three further reviews of approaches to measuring continuity of care, including articles of measures published up to 2002^{23, 24, 35}, the authors confirmed the limitations observed by Jee and Cabana in the use of individual-based or visit-based chronological measures of continuity of care. These indices of care typically measure the duration or frequency of contact with a regular provider of care, assess how care is concentrated among different providers or assess consecutive visits with the same provider. These measures therefore reflect structural characteristics of continuity of care rather than interpersonal continuity of care³⁵.

In terms of density and dispersion measures, the Usual Provider Continuity index (UPC¹¹⁹) which captures the concentration of patient care with particular providers, defined by the fraction of visits to a usual provider, and the Continuity of Care index (COC¹²⁰), which captures the concentration of visits (i.e. dispersion) with different providers, were reported to be the two most commonly used individual-based and visit-based measures of this type. The Sequential Continuity Index (SECON¹²¹), which can be used as a visit-based measure, is the most widely used measure to ascertain the extent of consecutive visits with the same provider. Averaging visit or individual-based continuity indices produces population measures of continuity of either visits or individuals. The authors argue that chronological measures are proxy measures of different underlying types of continuity and not separate dimensions of continuity. Counting the number of providers seen is a crude approach to determining dispersion of care and consideration of the strength of the doctor-patient relationship is not taken into account.

Relational Measures: Two reviews described widely used methods for examining the strength of patient-provider relationships. However, in both reviews the authors did not report the psychometric properties of the instruments.

According to two reviews^{23, 24} the domain most often assessed relates to 'affiliation'. From the authors' descriptions of the measurement approaches to this aspect of continuity, and from a review of the empirical literature, affiliation assessment is mostly limited to one or two simple questions on how often the patient has seen the same doctor/provider and typically measured by modified 4-point Likert scales ranging from "always" to "rarely or never"¹²², or measured as "yes", "no" to whether the patient sees the same doctor¹¹⁵. Although responses are not verified, positive answers are assumed to reflect relational continuity²⁴.

Subsequent to the publication of the reviews, another measure of continuity had been developed. The Consultation Quality Index-2¹²³, described as a measure of holistic interpersonal care in general practice, incorporates a measure of continuity of care derived from responses to a single question 'how well do you know the doctor you are going to see (or have seen) at the consultation'. However, research on measuring continuity of care with single item responses may be less reliable.

The same reviews^{23, 24} considered interpersonal (or relational) continuity measures that can be described as 'second generation' instruments, and which have solved some of the problems associated with the continuity indices and single item patient questions. The development of The Perception of Continuity (PC¹²⁴) scale, containing 23 items, was based on a theory of continuity. Continuity of medical care is conceptualised as a patient's attitude towards health care services rather than based on visits to the same provider. Reid et al (2002)²³ report the inclusion of subscales measuring knowledge, trust, comfort and additional relational attributes.

The reviews identified three more recent instruments that were designed to measure specific components of primary care from the perspective of patients. Although these instruments have not been designed specifically to measure continuity of care, they do include a continuity of care subscale and these have been used in numerous studies to measure the strength of the provider-patient relationship. For example, the Components of Primary Care Index (CPCI¹²⁵), a 20-item research tool, measures the patient's preference to see their regular physician as one of four domains developed to assess the delivery of aspects of primary care. The Primary Care Assessment Survey (PCAS¹²⁶), a 51-item patient-completed questionnaire comprising seven domains of primary care from 11 subscales, includes three items measuring the duration of the patient's relationship with a primary physician and how often the patient visits the primary physician (i.e. longitudinal and visit-based continuity). The strength of the doctor-patient relationship is assessed from three scales (longitudinal continuity, interpersonal treatment and trust). The Primary Care Assessment Tool Adult Edition (PCAT-AE¹²⁷), a 74 item instrument which includes 20 items representing 'longitudinality-interpersonal relationships', measures the quality of primary care experience. All three instruments were developed in the USA and based on either primary care adult patients or low-income adult patients in one study¹²⁷.

Subsequent to the publication of the two reviews^{23, 24}, a questionnaire has been developed that has the potential to investigate patient preferences and choices relating to different aspects of primary care, including continuity¹⁶. Patients are asked to respond to hypothetical health scenarios and choose between pairs of options relating to different aspects of care and continuity. Informational and longitudinal continuity are topics covered by the Patients' Choices Questionnaire¹⁶. The authors did not report on the psychometric testing of this measure.

Condition Specific Measures: A few validated measures assessing continuity of care from the patient's perspective and developed within specific patient populations were identified. Of the four validated continuity of care measures from the patient's perspective, two were relevant to diabetes care, one was developed for mental health services, and one had been specifically validated for use with cardiac populations in the transition from hospital care to home. The Heart Continuity of Care Questionnaire (HCCQ) evaluates continuity of care associated with a diagnosis of congestive heart failure and atrial fibrillation¹²⁸). The Diabetes Continuity of Care Scale (DCCS¹¹⁸) and the Experienced Continuity of Care for Diabetes Mellitus (ECC-DM^{14, 39}) scale were developed to evaluate continuity of care in patients with a diagnosis of diabetes and the Alberta Continuity of Services Scale (ACSS-MH¹²⁹) was specifically validated for use with people using community mental health services in Canada. The HCCQ and ACSS-MH instruments have not been developed or validated for primary care settings. Of the two instruments, the HCCQ contains informational and management components of continuity.

Description of the Instruments: The Diabetes Continuity of Care Scale (DCCS) is a 47-item self-report scale containing five domains: access, care by doctor (13 items), care by other healthcare professional (12 items), communication between healthcare professionals (5 items), and self-care (7 items). Each item is scored on a 5-point Likert scale.

The Experienced Continuity of Care for Diabetes Mellitus (ECC-DM) is a 19-item self-report scale divided into four continuity dimensions: longitudinal, flexible, relational, and team and cross-boundary continuity. Each item has six Likert-type scale response options, with scores of zero to 100 (worst to best score).

Psychometric Qualities: The two instruments have been subjected to psychometric evaluation by the developers. Content validity, readability, reliability and internal consistency were demonstrated for each of the instruments. Floor or ceiling effects were not reported. Experts and patients were involved in the selection process of items for the ECC-DM and the DCCS, indicating content validity.

Reliability and Internal Consistency: Cronbach's alpha coefficients for the four subscales of the ECC-DM ranged from 0.65 (longitudinal continuity) to 0.98 (relational continuity), indicating that there may be some redundancy among items on the relational continuity subscale. Cronbach's alpha coefficients for the DCCS total scale and ECC-DM total scale were respectively 0.89 and 0.91. Test-retest reliability was demonstrated for the DCCS only.

Summary

There are few useful measures of continuity of care with which to evaluate patient experiences and perceptions of continuity of care or to examine the relationship between continuity of care and patient outcomes. A major barrier to the development of useful and practical measures of continuity of care includes the vast diversity in definitions of continuity of care. Some progress has been made, resulting in useful measures that have been developed within a multidimensional framework and which are based on definitions of continuity that are beginning to achieve acceptance in the field. However, most of those that are available, and have the potential to produce useful results specific to continuity of care in general practice, have been developed as patient-based condition specific measures. Given that evidence is building that patients with chronic or long-term illnesses particularly value continuity suggests that condition specific measures are warranted.

Table 4. Instruments developed to measure continuity of care from the patient's perspective

Reference	Measures	Framework & concept	Scale domains	Perspective
Baker et al (2001) ¹⁶	Patients' Choices Questionnaire	Experienced continuity (Multidimensional concept)	Aspects of primary care; relational continuity; informational continuity; longitudinal continuity	Patient
Gulliford et al (2006) ³⁹	Experienced Continuity of Care for Diabetes Mellitus (ECC-DM)	Experienced continuity (Multidimensional concept)	Longitudinal continuity; flexible continuity; relational continuity; team and cross-boundary continuity	Patient
Dolovich et al (2004) ¹¹⁸	Diabetes Continuity of Care Scale (DCCS)	Experienced continuity (Multidimensional concept)	Access/getting care; care by doctor; care by other healthcare professional; communication between healthcare	Patient

Reference	Measures	Framework & concept	Scale domains	Perspective
			professionals; self-care	
Flocke, (1997) ¹²⁵	Components of Primary Care Index (CPCI)	Aspects of Primary Care; includes continuity of care domain	Primary Care domains, including patient preference to see regular physician	Patient
Safran et al (1998) ¹²⁶	The Primary Care Assessment Survey (PCAS)	Aspects of Primary Care; includes continuity of care domains	Primary Care domains, including Longitudinal and visit-based continuity of care	Patient
Shi et al (2001) ¹²⁷	The Primary Care Assessment Tool Adult Edition (PCAT-AE)	Aspects of Primary Care; includes continuity of care domains	Primary Care domains, including longitudinal and interpersonal continuity of care	Patient

Discussion

The review presented a broad overview of research examining the role of continuity of care in primary care, identify definitions of continuity and the methods used to measure it, summarise patients' views of continuity and the evidence base on the relationship between continuity and patient outcome.

The preoccupation of many researchers has been on identifying common definitions across the field of continuity of care rather than developing a firm theoretical understanding of the concept. Conceptual clarity and standardised operational definitions have yet to be achieved. This may explain the wide variation found in the methods used to study continuity of care. A more precise definition and improved methods for measuring continuity of care are needed to support research efforts in understanding the effects of continuity of care on patient outcomes.

The evidence base for the benefit of continuity of care is difficult to interpret, with much of the evidence consisting of small studies and the application of different outcome measures and diverse patient populations. The varied study settings make it difficult to provide recommendations for patients in general practice when the majority of research has been conducted in secondary care and in different health care systems. More attention also needs to be given to the development of self-report tools from the patient's perspective and validating them across a range of disease-specific conditions.

Research suggests that patients value seeing the same GP^{7, 84, 130}. Interpersonal continuity of care is especially important to patients with chronic or long-term illnesses and to patient groups defined as 'vulnerable' (that is, parents with young children, the elderly, the less educated and less wealthy within a society and people with chronic condition). However, few studies have examined the relative importance of aspects of primary care in relation to continuity of care. It is apparent from this limited evidence base that patients with minor, acute problems are willing to trade-off continuity of care for rapid access. However, there are methodological issues that need to be considered when eliciting patient preferences. Willingness to pay approaches using monetary sacrifices as indicators of the value of continuity of care may provide misleading results if researchers fail to adjust for income differences.

There is some evidence that continuity of care is associated with higher levels of patient satisfaction with care and improvements in the process of clinical care provided¹⁷. However, the importance of continuity of care to health care outcomes is more ambiguous. Demonstrating that continuity of patient care improves health status outcomes is difficult due to the contribution of multiple factors that influence health outcomes as well as other features of care⁸⁹.

Conclusion

There is evidence that patients value continuity of care; however, some patients in particular circumstances value speed of access to health care over continuity of care. Assessing patient preferences and developing quality indicators to assess important aspects of continuity of care will depend on the extent to which valid and easy to use measures can be identified. However, despite decades of research, there is a lack of agreement on how to define the term and a diversity of ways to measure it.

Table 5. Existing systematic reviews of the relationship between continuity of care and process and healthcare outcomes

Reviews of continuity of care and care outcome

Authors	Patient setting	Search terms	Review methods	Data extracted	Results and conclusions
Cabana and Jee (2004) ¹⁷	Mixed patient groups, primarily in USA. Healthcare providers included primary care specialties (family medicine), paediatrics, general practice, internal medicine and primary care physicians	MeSH terms used: continuity of patient care or continuity of care	Searched MEDLINE, ERIC, and PSYCHINFO databases; followed up reference citations and outcomes Timeframe covered by search: January 1966 to January 2002 Inclusion and exclusion criteria reported Selection criteria independently applied by two researchers Selection differences resolved by informal consensus and kappa score calculated Data abstraction conducted by two independent reviewers	Reports study design, location, population, continuity of care	196 English language articles identified, of which 18 selected for inclusion Mixed results for costs: increased continuity associated with decreased health care expenditure in one cross-sectional study, and in another similar study significance of findings depended on measurement method Review reports consistent association between continuity and patient satisfaction, based on the results of four studies Review reports increased continuity improves receipt of preventive services and decreases hospitalisations and emergency department visits
continued					

Reviews of continuity of care and care outcome

Authors	Patient setting	Search terms	Review methods	Data extracted	Results and conclusions
Saultz and Albedaiwi (2004) ¹⁸	Mixed patient groups primarily in USA. Other primary care settings include Australia, Norway and UK	MeSH terms used: continuity of patient care	Searched MEDLINE database; followed up reference citations Timeframe covered by search: January 1966 to April 2002 Selection criteria related to interpersonal continuity and patient satisfaction Selection criteria applied by first author and data extracted using bibliographic database Study quality assessed by 2 reviewers independently and disagreements resolved by consensus	Reports study design, setting, clinical outcomes measured, outcome improvement, findings and quality of research	142 English language citations identified, of which 30 articles were selected (reporting 22 original studies) Differences in patient satisfaction measures used precluded meta-analysis Four RCTs reported improved patient satisfaction in study groups with higher continuity of care Study methods flawed by confounding factors, including unexamined differences between groups and continuity measured in only two of the trials applying continuity indices Cohort studies reported mixed results; two articles showed significant relationships between patient satisfaction and improved continuity and two reported non-significant findings 11 out of 12 cross-sectional surveys reported improved patient satisfaction and interpersonal continuity Authors conclude that studies finding a relationship between continuity of care and patient satisfaction have not explored a causal direction, suggesting
continued					

Reviews of continuity of care and care outcome

Authors	Patient setting	Search terms	Review methods	Data extracted	Results and conclusions
Saultz and Lochner 2005 ¹⁹	Mixed patient groups primarily in USA. Other primary care settings include Australia, Canada, Finland, Norway and UK	MeSH terms used: continuity of patient care	Searched MEDLINE database; followed up reference citations Timeframe covered by search: January 1966 to April 2002 Selection criteria related to interpersonal continuity and general medical care Selection criteria applied by first author and data extracted using bibliographic database Study quality assessed by 2 reviewers independently and disagreements resolved by consensus	Reports study design, setting, clinical outcomes measured, outcome improvement, findings and quality of research	2,424 English language citations identified, of which 379 were obtained, 41 articles selected (reporting 40 original studies) Differences in study methods precluded meta-analysis Majority of studies reported multiple outcomes 23 studies reported positive association for all outcomes, 12 with positive association for at least 1 outcome examined, 2 with worse outcome and 5 with no association Delivery of preventive care was the most common outcome examined (12 studies examining 22 outcomes), followed by hospitalisation rate (9 studies, 11 outcomes), quality of doctor-patient relationship (5 studies, 5 outcomes), chronic illness management indicators (4 studies, 8 outcomes), and maternity care (4 studies, 16 outcomes) Interpersonal continuity associated with significant improvement in some care outcomes: preventive services and hospitalisation, but research limited by
continued					

Reviews of continuity of care and care outcome

Authors	Patient setting	Search terms	Review methods	Data extracted	Results and conclusions
Worrall and Knight (2006) ²¹	Older patients in receipt of primary healthcare, primarily in USA. Other settings included one study conducted in The Netherlands	MeSH terms used: continuity of patient care, elderly, primary care and outcomes	Searched MEDLINE, EMBASE and CINAHL databases; followed up reference citations Timeframe covered by search: January 1970 to July 2005 Selection criteria related to people 50 years or older, primary care settings and patient outcomes Insufficient details reported on study selection methods and data abstraction Study quality assessed by 2 reviewers	Reports study design, population and intervention and type of continuity, and outcome measures	126 English language articles identified, of which 5 were selected Few well designed studies on continuity of care for the elderly Observational studies cannot provide answers to causal direction of associations between continuity and outcomes Studies have measured process rather than outcomes of care Results of RCTs suggest patients in the continuity group were more likely to have fewer emergency admissions or visits and shorter average stays in hospital Cross-sectional study results showed female patients who experienced greater continuity felt healthier and had fewer symptoms by self-rated health status reports Authors conclude there is inconclusive evidence for the benefit of continuity of care for elderly patients
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