Measuring care coordination: health system and patient perspectives

Report prepared for the Main Association of Austrian Social Security Institutions

by

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1. Introduction

1.1 Why measure care coordination?

Lack of coordination is widely considered to be one of the key causes of poor quality health care (Bodenheimer, 2008; Ovretveit, 2009). Care that is not coordinated can be harmful to patients and waste resources due to duplication of diagnostic tests, inappropriate polypharmacy and conflicting care plans (Bodenheimer, 2008). Fragmented care delivery is particularly ill-suited to meeting the health needs of people with one or more chronic conditions. These people require seamless care over extended periods of time and across sectors and care settings. Better care coordination has therefore become an explicit objective of health system reform in many countries (McKee and Nolte, 2009).

Evidence suggests that five organizational elements are critical to ensuring care coordination (Conrad and Dowling, 1990; Shortell et al., 2000; Skelton-Green and Sunner, 1997; Vázquez et al., 2009). The absence of these elements might produce discontinuity within the health system:

- a shared vision of the health system’s goals and strategies across care levels (primary, secondary, tertiary care) (Alexander et al., 1995);
- methods for resource allocation that align incentives for care coordination (payment system) (Shortell et al., 2000);
- an organic structure with mechanisms that enhance communication between health professionals involved in the care process (Longest and Young, 2000);
- a common culture and leadership with values oriented at teamwork, collaboration and best performance (Barnsley et al., 1998; Kornaki and Silversin, 1998);
- a health care model based on strategies for promoting primary care (PAHO, 2010).

Health systems can address these critical elements by introducing an array of interventions at different levels of the health system (Vázquez et al., 2005). The
absence or presence of effective interventions may provide further relevant information about care coordination in a given context.

- **Macro-level**: policies and regulatory mechanisms to develop integrated health care organizations; integrated purchasing strategy, including performance-based evaluations and capitation payment, that fall under the responsibility of health authorities and regulatory bodies;

- **Meso-level**: health organizations’ strategic plans; functional integration and coordination mechanisms for managerial functions (e.g. integrated management strategies, shared management committee) to be developed and implemented by health managers;

- **Micro-level**: the introduction of a single mechanism that can be informational (integrated information system), managerial (clinical guidelines and pathways) or administrative (referral mechanisms); or a combination of coordination mechanisms in a comprehensive program (e.g. disease and case management programs), to be developed and implemented by health managers and professionals.

Care coordination can be seen as part of a broader strategy to improve quality in health care delivery and, ultimately, to strengthen the performance of the health system (McAdam, 2008; Ovretveit, 2011). It is needed in three contexts (Ovretveit, 2011):

- within organisations (such as hospitals) to align the provision of different services;

- between organisations, to link care across organisational boundaries (e.g. when patients are referred or professionals require patient information held by other organisations);

- at the patient level, to enable people with chronic conditions to have access to the right care at the right time delivered by appropriately trained professionals.

Policies designed to promote care coordination should be accompanied by evaluation of their results as part of the measurement of the health system’s performance. Smith et al. (2009) identify two reasons for measuring performance: first, to foster improvement in the health sector (to diagnose problems, understand causes, identify areas for
improvement, facilitate policy implementation); and second, to ensure accountability (through increased transparency over how and where health care resources are used and holding stakeholders to account for service quality and efficiency).

Measuring care coordination is challenging precisely because it is the product of multiple organisations and providers. Nevertheless, a range of measurement tools is increasingly available (Armitage et al., 2009). This report discusses different approaches to measuring care coordination and discusses implications for Austria.

1.2 Conceptualising care coordination

The conceptualisation of care coordination is hampered by the lack of a single accepted definition and blurred boundaries with related concepts such as “integrated care”, “continuity of care”, “patient-centred care” and “seamless care”. These terms are often used interchangeably, although they may mean slightly different things (Kodner, 2009; Kodner and Spreeuwenberg, 2002). However, all of these concepts are underpinned by the recognition that high-quality health care for people with chronic conditions is not the result of the actions of one provider at a single point in time, but the result of an ongoing process involving multiple providers over extended periods of time (Nolte and McKee, 2008). The terms used in this report are defined in the following paragraphs.

Care coordination

This is defined as the harmonious connection of the different services needed to provide care to a patient across the care continuum to achieve a common objective (Starfield, 2002). Care coordination usually refers to clinical aspects and focuses, in particular, on the interactions between providers over time and across settings (Fulop et al., 2005). Health care organisations may opt for different strategies to coordinate care, ranging from the introduction of a single mechanism, such as an integrated information system, clinical guidelines or referral mechanisms, to a combination of mechanisms in a comprehensive program, such as disease or case management (Mintzberg, 1990).

Conceptually, one can distinguish between at least two interrelated types of care coordination:
Informational coordination refers to the transfer and use of the clinical information needed to coordinate activities between providers. In order to achieve effective informational coordination, the mere transfer of data is not enough; the information also has to be analysed and taken up by decision-makers (Reid et al., 2002; Vargas et al., 2011). As a result, informational coordination across care levels helps to reduce unnecessary duplication of services and tests and harmful application of medical supplies such as medicines.

Managerial coordination is the provision of care in a sequential and complementary way. It is based on a care plan which extends across the care continuum and is shared by the care levels and providers involved in a patient’s care delivery (Reid et al., 2002; Vargas et al., 2011).

Care integration

This is considered to be the highest degree of coordination (Shortell et al., 2000). It can be defined as “a concept bringing together inputs, delivery, management, and organisation of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve services in relation to access, quality, user satisfaction and efficiency” (Groene and Garcia-Barbero, 2001). Care integration can be seen as a comprehensive process that aims to address fragmentation in health care delivery.

Integrative measures can involve clinical aspects, but may also encompass wider electronic integration of health information systems, functional integration (eg of management functions), and financial integration (eg of provider and purchaser functions) (Amelung et al., 2009). Different degrees of integration can be described in terms of a continuum. According to Leutz (1999), at one end of this continuum are loose linkages, such as basic forms of information exchange. At the other extreme is a closely integrated organisation with clearly specified mutual responsibilities and usually some form of financial integration. In between, intensity of connections and coordination of services across health organisations may vary, in terms of different types of networks with differing degrees of commitment.
Continuity of care

This can be defined as the degree to which patients experience the provision of care over time as being coherent and interlinked (Reid et al., 2002). Continuity is relevant where different providers care for one patient. It is the result of care coordination as seen from the patient’s perspective (Haggerty et al., 2003; Reid et al., 2002) and may take the following forms (Table 1):

- **Relational continuity** refers to an on-going, therapeutic relationship with one or more providers spanning different health care episodes;

- **Informational continuity** links past with current care by transferring and using information of the patient’s medical history and personal circumstances;

- **Managerial continuity** is the perception of the degree to which health services are delivered in a coherent and complementary manner, in order to achieve health goals.

Table 1. Continuity of care: types and dimensions

<table>
<thead>
<tr>
<th>Relational continuity</th>
<th>Informational continuity</th>
<th>Managerial continuity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consistency of personnel</td>
<td>Information transfer and use</td>
<td>Consistency of care</td>
</tr>
<tr>
<td>Established patient-provider relationship</td>
<td>Accumulated knowledge</td>
<td>Flexibility and accessibility across care levels</td>
</tr>
</tbody>
</table>

Source: Adapted from Reid et al. (2002).

1.3 Report objectives and methods

This report aims to:

- identify different approaches to analysing and measuring care coordination
- illustrate international experience
- highlight implications for Austria

A literature review was conducted based on search terms developed with a research librarian and expert in systematic reviews. The search terms were refined during the research. The main search terms included: “integrat* care”, “integrat* health care”,

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“care coordination”, “continuity of care”, “chronic conditions”, “measur*”, “quality indicator” “performance indicator” and “evaluat*”.

The report’s search strategy included:

- review of relevant electronic databases (Web of Science, PubMed)
- hand-searching key journals and conference papers
- review of other Internet resources (eg Google, Open Grey)
- hand-searching bibliographies of selected articles and papers

Inclusion criteria related to publication of relevant literature in English, German, French, Spanish or Dutch, such as peer-reviewed journal articles, reports, book chapters, conference abstracts, theses or informal reports relevant to people with chronic conditions. Title and abstracts were screened, and if a paper was deemed relevant on that basis, the full text was retrieved and relevant information was extracted in a standard format.

1.4 Structure of the report

Section 2 summarises key findings from the literature review regarding different approaches to measuring care integration, data sources and requirements.

Section 3 highlights implications and options for action for Austria based on the conceptual analysis and the international review.

Appendices to the report provide information on the experience of three countries – England, the Netherlands and the Catalonia region of Spain – which have made recent advances in measuring care coordination (Appendix A) and a summary of performance indicators (Appendix B).
2. Measuring care coordination: approaches, data sources and requirements

2.1 Approaches to measurement

This section focuses on care coordination and continuity of care: two dimensions that provide complementary information from distinct perspectives. Care coordination concerns the health system or provider perspective. Continuity of care concerns the patient’s perspective.

The framework could be extended to include access to health care, which is an important element when measuring the performance of integrated delivery organisations (Vázquez et al., 2009). However, as access is closely entwined with continuity of care (Haggerty 2002), particularly managerial continuity (Waibel et al., 2012c), it is implicitly analyzed within the suggested framework.

Irrespective of the adopted framework, the scope of measuring integrated care needs to be defined in relation to different levels of care. Traditionally, approaches to measuring care integration have tended to focus on the interface between outpatient and inpatient care. While overcoming the outpatient-inpatient sectorial divide may be a key goal for policy intervention and measurement, a comprehensive framework would extend to various other sectors, settings and stages in the disease pathway. These may include social care, domiciliary and home care, mental health care, hospice and other palliative care (Jonas et al., 2012; McKee and Nolte, 2009).

2.2 Analysing care coordination: the health system perspective

Analysis of care coordination should consider the measurement of two interrelated types (Reid et al. 2002; Vargas et al. 2011):

- **Informational coordination** across care levels can be analysed by examining the information recorded, mechanisms for information transfer, and their use by subsequent care providers (Devers et al. 1994).
Managerial coordination can be analysed by examining whether care is provided in the correct sequence at the proper point in time (longitudinal follow-up) and with clinically coherent decisions (consistency of care across providers) (Reid et al. 2002).

Measurement strategies can adopt a qualitative or quantitative approach, or combine both in a mixed-methods study (Table 2).

Table 2: Summary of approaches to measuring care coordination

<table>
<thead>
<tr>
<th>Study design</th>
<th>Data source</th>
<th>Selected available tool</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Qualitative</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-depth interviews</td>
<td>Health professionals and managers</td>
<td>Topic guides, eg McEvoy et al. (2010); Sandström et al. (2004); Waibel et al. (2012a)</td>
</tr>
<tr>
<td>Focus groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Case studies of health organisations:</td>
<td>- Health professionals and managers</td>
<td>Framework for the analysis of integrated delivery organisations (Vázquez et al. 2009)</td>
</tr>
<tr>
<td></td>
<td>- Clinical and administrative records</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Policy documents, legislation, organisation charts, plans, agreements</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Records analysis</td>
<td></td>
</tr>
<tr>
<td><strong>Quantitative</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey</td>
<td>Health professionals</td>
<td>Primary Care Assessment Tool: provider expanded edition (Starfield 2008) (^1)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>ICU Nurse-Physician Questionnaire (Shortell 1991) (^2)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Actual versus optimal integration (Ahgren and Axelsson, 2005)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Assessment of Chronic Illness Care (ACIC; Bonomi et al., (2002); Cramm et al., (2011, 2012)</td>
</tr>
<tr>
<td>Records analysis</td>
<td>Clinical and administrative records</td>
<td>Set of indicators is currently validated in the Catalan context (^3)</td>
</tr>
<tr>
<td>(indicators)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: adapted from Vázquez et al. (2009).


Qualitative approaches

Qualitative approaches can help to identify enabling and hampering factors associated with care coordination and the use of established coordination mechanisms. Furthermore, qualitative methods help to provide an insight into how specific local conditions influence the outcomes of a given programme for improving care coordination (Nolte et al., 2012). Results of qualitative studies can also be used to refine the development of quantitative data collection instruments and to interpret the results from surveys or performance indicators.

The qualitative analysis of care coordination is often based on health professionals’ and/ or managers’ perspectives by means of in-depth interviews or focus group discussions (Strandberg-Larsen 2009, Mintzberg 1999). A (multiple) case study of selected health organisations or areas may also be an appropriate study design (Vázquez 2009).

Research supports the importance of internal and external factors in positively or negatively influencing health care coordination (Shortell, 1997; Skelton-Green and Sunner, 1997). Vázquez et al. (2009) summarize the internal organisational elements that are critical for care coordination to exist: an organic structure with mechanisms that enable efficient communication between different health professionals (Longest 2000); a common culture and leadership with values oriented toward teamwork, collaboration, and performance (Kornaki and Silversin, 1998); and an internal resource allocation system that aligns the incentives of health services to the global objectives of the network (Shortell et al., 2000). External elements that can influence care coordination or integration include: policy goals and strategies, public insurance characteristics (sources, benefit packages, and access conditions) and funding allocation methods (Vázquez et al., 2005). Information about internal and external factors can be obtained through documentary analysis and interviews with key actors (Vázquez and Vargas, 2009).

Topic guides for semi-structured interviews on care coordination have been published (Table 3). McEvoy et al. (2010) developed a topic guide that focused on the evaluation of a case management service for high-intensity services users, including aspects such
as the role of the case manager, working relationships and internal organisation. The topic guide by Henao et al. (2002) covered health professionals’ perception of the concept of care coordination, their opinion on care coordination in the integrated health care networks where they are working, influencing factors and strategies for improvement. Waibel et al.’s topic guide (2012a) was elaborated for the triangulation of in-depth interviews with COPD patients within a multiple case study design. The topic guide included the reconstruction of care trajectories of COPD patients and questions on informational and managerial COPD care coordination. When considering the use of qualitative methods for the analysis of care coordination, the elaboration of a topic guide should be based on a literature review on relevant papers taking into account the specific research objectives and context.

Table 3: Content of selected interview topic guides on care coordination

<table>
<thead>
<tr>
<th>Domain/Subject area</th>
<th>Objectives</th>
<th>Sample questions/probes used</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction</strong></td>
<td>Basic biographical and demographic information</td>
<td>Age, personal professional background</td>
</tr>
<tr>
<td><strong>Meaning and importance of care coordination</strong></td>
<td>Meaning of care coordination Importance of care coordination</td>
<td>How would you describe care coordination to a stranger? Why is care coordination important to you?</td>
</tr>
<tr>
<td><strong>Managerial care coordination</strong></td>
<td>Perceptions of relationships and coordination between physicians Perceptions of the utility and use of specific care coordination mechanisms</td>
<td>How would you describe, both the nature and the quality of your relationship with other service providers you work with? Can you tell me about the internal organisation of the service and how you work as a team? Do you use any mechanisms/strategies to coordinate care across care levels? What are the major facilitating factors and barriers you have encountered in trying to deliver care coordination using these mechanisms/strategies?</td>
</tr>
<tr>
<td><strong>Informational coordination</strong></td>
<td>Perceptions of information transfer between physicians and its use</td>
<td>How is information shared between service providers? Are there any other mechanisms put in place for sharing information (formal and informal communication). What kind of information is shared? What factors enhance/distract from informational coordination?</td>
</tr>
<tr>
<td><strong>Concluding questions</strong></td>
<td>Suggestions for improvement Other topics that may not have been covered</td>
<td>If you could change anything about the care coordination process, what would it be? Are there any other issues that you would like to comment on?</td>
</tr>
</tbody>
</table>

Source: Adapted from McEvoy et al. (2010); Henao et al. (2008); Waibel et al. (2012a).
Quantitative approaches: surveys

To measure care coordination using quantitative methods, surveys with health professionals or system representatives are often used (Strandberg Larsen, 2011):

- Some questionnaires focus on one care level or unit but include items on care coordination across care levels (e.g., the Primary Care Assessment Tool: Provider Expanded Edition; ICU Nurse-Physician Questionnaire; Care Coordination Services in Pediatric Practices) or on one specific disease or chronic care (Breast Cancer Patient and Practice Management Process Measures Surgeon Survey; Continuity of Care Practices Survey (substance use disorder); Assessment of Chronic Illness Care).

- Other questionnaires have been developed to determine the cost of care coordination (Care Coordination Measurement Tool) (AHRQ, 2010).

A tool that comprehensively analyses care coordination across care levels and including both coordination types might need to be developed and validated within the study context.

Here, we explain three questionnaires in detail (see also Table 4):

- The Primary Care Assessment Tool: Provider Expanded Edition (PCAT PE) measures primary care quality and the extent to which it meets consumer needs, as identified from the provider perspective. This tool embraces 153 items with coverage across four domains of primary care: longitudinality, accessibility, comprehensiveness and coordination. Three aspects of care follow from the achievement of the four main aspects, and are sometimes also included in assessments of primary care: family-centered care, community-oriented care and culturally competent care (AHRQ, 2010). The coordination domain consists of a total number of 15 items regarding the information systems and integration of services (for examples see Table 4) (Starfield and Shi, 2008). The tool was administered by mail to 101 providers of various health care settings in Washington D.C. Results indicated that the tools measured key primary care domains with reliability and a consistency that suggested validity and that they had the ability to
detect differences across various types of provider organisations and facilities with regard to primary care delivery (Starfield et al., 1998).

- The ICU (Intensive Care Unit) Nurse-Physician Questionnaire measures clinician perceptions of managerial (leadership, culture) and organisational (coordination, communication, conflict management) factors affecting ICU performance. This tool includes 218 items consisting of 11 sections, however, a shorter version is also available (85 items and 6 sections) (Shortell et al., 1991). Although the questionnaire focuses on care coordination within the ICU, one section measures care coordination between the ICU and other hospital units. This section includes the perception of the effectiveness of different mechanisms such as computerised information systems, daily staff rounds or standing committees (see Table 4). The tool demonstrates high reliability and validity for almost all scales (AHRQ, 2010; Shortell et al., 1991) and has been used in different studies (Manojlovich, 2005; Manojlovich and DeCicco, 2007; P. Miller, 2001).

- The Assessment of Chronic Illness Care (ACIC) questionnaire is designed as a measurement tool for the improvement of health care for patients with long-term illnesses. The questionnaire evaluates strengths and weaknesses of care delivery for chronic illnesses from the system representatives’ perspective, and embraces 34 items that and covers six areas: community linkages, self-management support, decision support, delivery system design, information systems, and organisation of care (Bonomi et al., 2002). The new version (Version 3.5) includes six additional items that address how well a practice team or organisation integrates the Chronic Care Model elements - so, for example, whether guidelines are used to inform self-management programs for patients or whether registries are used to perform care functions like routine follow-up. Hence, different items can be used for the analysis of managerial coordination as well as informational coordination (Part 6 on the clinical information system). Some these items are presented in Table 4. The ACIC questionnaire has been validated and used in different countries such as the United States (Bonomi 2002), Thailand (Gomutbutra et al., 2012) and the Netherlands (Cramm et al. (2011); see also case study of the Netherlands).
Table 4: Care coordination questionnaires

<table>
<thead>
<tr>
<th>Care coordination types</th>
<th>Primary Care Assessment Tool: Provider Expanded Edition (Starfield and Shi 2008)</th>
<th>ICU (Intensive Care Unit) Nurse-Physician Questionnaire (Shortell et al. 1991)</th>
<th>Assessment of Chronic Illness Care (ACIC) (Bonomi 2002)</th>
</tr>
</thead>
</table>
| Informational coordination | • When patients are referred, do you give them any written information to take to the specialist?  
• Do you receive useful information about your referred patients back from the specialists or special services?  
• Are patient records available when you see patients? | • How effective is one-to-one communication between  
ICU staff and members of other units?  
• How effective are computerised information systems? | • Information about relevant subgroups of patients needing services is provided routinely to providers to help them deliver planned care  
• Registry (list of patients with specific conditions) is tied to guidelines which provide prompts and reminders about needed services. |
| Managerial coordination | • Do you use the following methods to assure that indicated services are provided?  
A) Printed guidelines in patients’ records  
B) Periodic medical record audits, etc. | • Overall, our unit functions very well together as a team.  
• How effective are task forces and standing committees involving members of the ICU and other units? | • Continuity of Care is a high priority and all chronic disease interventions include active coordination between primary care, specialists, and other relevant groups.  
• Follow-up is customised to patient needs, varies in intensity and methodology (phone, in person, e-mail) and assures guideline follow-up.  
• Practice team functioning is assured by teams who meet regularly and have clearly defined roles including patient self-management education, proactive follow-up, and resource coordination and other skills in chronic illness care. |

Quantitative approaches: records analysis

To measure care coordination using records analysis, this may take the form of identifying a care pathway (see section 3.1, England case study) or data linkage of different medical or administrative data sets can further be used to measure care coordination (Jonas et al., 2012). Records analysis involves the use of performance indicators which assess aspects related to the structure, process and outcome of the coordination between levels needed to guarantee informational and managerial continuity across the health care continuum (Terraza 2006). A list of examples of
structure, process and outcome indicators for general performance measurement and their relative strengths and weaknesses is provided in Appendix B.

The purpose and use of *structure indicators* relates to understanding the resources that are available to deliver integrated care. The interest may lie on specific structures that are assumed to facilitate coordination, eg related to organisational aspects (eg availability of multi-disciplinary teams, proportion of physicians organised in care networks) or information systems (eg proportion of practices with a shared informational infrastructure across sectors with hospitals and other providers such as physiotherapists or pharmacists). Policy-makers may also be interested in the degree to which existing structures impact on improved care coordination processes and outcomes. A model for measurement of structural health care integration in Sweden is provided by Ahgren and Axelsson (2005); it operationalises the continuum of integration into a ratio scale of different categories from full segregation to full integration. The structural measures included are clinical guidelines, network managers or patient referrals. The aim is to compare actual and optimal degrees of integration both within and between different organisations (Ahgren and Axelsson 2005).

*Process indicators* have an analytic value in examining to what extent better coordinated processes of service delivery actually result in improved health and economic outcomes (Ryan and Doran, 2012); whereas *outcome indicators* give information about the extent a policy has achieved its objectives, and, thus, are what ultimately matters most to policy-makers and patients. Outcome indicators are important both before and after policy implementation. Before implementation, they can provide a baseline for measuring the current situation. During implementation, outcome measurement seeks to examine the degree to which integrated care structures and processes do indeed have an impact on outcomes that are important to policy-makers.

It is generally difficult to identify indicators that specifically focus on the processes and outcomes of care coordination, as available measures tend to apply to service delivery performance more widely. Available measures of care coordination also commonly refer to one care level (often primary or ambulatory care) and do not explicitly take into account the health system’s contextual factors (McDonald 2007; McDonald 2010; Strandberg-Larsen 2009). So far, no reliable and sufficiently validated set of indicators
to evaluate systematically care coordination aspects has been developed. A set of structural, process and outcome indicators, that incorporates the analysis of the two coordination types, is however currently being validated in the Catalonian context (Vargas et al., 2011-2013) (see also section 3.3, case study of Spain).

2.3 Analysing continuity of care: the patient’s perspective

Continuity of care is usually seen as part of patient-centeredness and addresses the extent to which health care is smoothly organised within providers and institutions. In contrast to care coordination, where much may go on ‘behind the scenes’ from the patient’s perspective, continuity of care should be analysed from the patient’s perspective (Arah et al., 2006). Measuring or analysing continuity across levels of care should be undertaken in a comprehensive manner by taking into account its three interrelated types (relational, informational and managerial; see Table 1). This facilitates understanding the elements which patients relate to continuity of care and their relevance, as well as identifying potential barriers to effective service delivery that might be due to eg lack of suitable coordination mechanisms (Freeman and Hughes, 2010; Reid et al., 2002; Uijen et al., 2010). Qualitative and quantitative approaches to measuring continuity of care are summarised in Table 5.

<table>
<thead>
<tr>
<th>Study design</th>
<th>Data source</th>
<th>Selected available tool</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Qualitative</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In-depth interviews</td>
<td>Health care users and their carers</td>
<td>Topic guides, eg Miller et al. (2009); Guthrie and Wyke (2006); Waibel et al. (2012b)</td>
</tr>
<tr>
<td>Focus groups</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Users’ case studies</td>
<td>Health care users (and health professionals for triangulation)</td>
<td>Topic guides see above</td>
</tr>
<tr>
<td>- in-depth interviews</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- records analysis</td>
<td>Patients’ clinical records</td>
<td></td>
</tr>
<tr>
<td><strong>Quantitative</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Survey</td>
<td>Health care users</td>
<td>CCAENA Questionnaires (Aller et al., 2012); Nijmegen Continuity Questionnaire (Uijen et al., 2011)</td>
</tr>
</tbody>
</table>

Table 5: Summary of approaches to measuring continuity of care

Source: adapted from Vázquez et al. (2009).

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Qualitative approaches

Continuity of care can be analysed comprehensively by using qualitative research methods to approach the perceptions of patients, their carers and relatives regarding their experiences with health services. Qualitative methods can also be used in addition to quantitative methods (e.g., patient surveys) to better understand and interpret these results.

In-depth interviews and focus groups are generally used for exploring the continuity of care phenomenon in new contexts (Freeman and Hughes, 2010). A case study design may be applied to understand continuity of care in its multifaceted manner by using different sets of information, i.e., a combination of different qualitative methods for triangulation of data (DePoy and Gitlin, 1994). The purpose of case studies is to gather comprehensive, systematic and in-depth information about each case of interest (Patton, 1990). A case of interest can be a patient with an acute or chronic condition who has been seen by different providers within the last months prior to the launch of data collection. In a multiple case study, analyses of two or more cases are conducted (DePoy and Gitlin, 1994), enabling the exploration of differences and similarities (Yin, 2003).

Various topic guides for semi-structured interviews on continuity of care have been published (Table 6). The topic guide by Miller et al. (2009) focuses on the perceptions and experiences of parents of children with complex chronic health conditions regarding continuity of care. Subject areas of the topic guide included patients’ meanings and overall evaluations of continuity, as well as perceived interactions with and between service providers. Guthrie and Wyke’s study (2006) examined patients’ perceptions of the value of personal (relational) continuity, rapid access, and the relationship between them in UK general practices. The elaborated topic guide embraces subject areas on relational continuity with the GP and managerial continuity, especially the analysis of access to care. Finally, Waibel el al.’s topic guide (2012b) was elaborated for a multiple case study of COPD cases regarding continuity of care in integrated health care networks. The topic guide first reconstructs the COPD patient’s trajectory within the network (diagnosis and treatment) and secondly examines their perception of relational continuity with primary and secondary care professionals, as well as of informational and managerial continuity of their COPD care within the
network. Subject areas, their objectives and sample questions of the three presented topic guides are summarised in Table 6.

Table 6: Interview topic guides for continuity of care

<table>
<thead>
<tr>
<th>Domain</th>
<th>Objectives</th>
<th>Sample questions/probes used</th>
</tr>
</thead>
</table>
| **Background of patient**       | Basic biographical and demographic information                              | • Tell me about: age, education, occupation, number of family members, household occupants  
• Tell me about your condition. When was it diagnosed? Which physicians have you seen?  
• Who else has been important for you during the care trajectory? |
|                                 | Description and knowledge about patient’s condition                         |                                                                                                                                                             |
| **Meaning and importance of continuity** | Meaning of continuity of care                                              | • There’s been a lot of talk lately about continuity of care. What does “continuity” mean to you?  
• Why is continuity of care/ this element important to you? |
|                                 | Importance of continuity of care                                           |                                                                                                                                                             |
| **Relational continuity**       | Perception of relationship with GP/secondary care professional              | • How is the relationship with your physician?  
• Is there any particular health professional you prefer (not) to see?  
• Do you always see the same physician? Why? |
|                                 | Perception of consistency of personnel in primary/secondary care.           |                                                                                                                                                             |
| **Informational continuity**    | Perceptions of information sharing between physicians                      | • How informed is physician about your health/antecedents/treatment or test done in the other care level?  
• Which physicians communicate with each other? How?  
• Do you think your GP/secondary care physician knows you? Why? |
|                                 | Perception of accumulated knowledge                                        |                                                                                                                                                             |
| **Managerial continuity**       | Perceptions of relationships and coordination between physicians           | • How does physician X know physician Y?  
• Do you think physicians collaborate? Why?  
• Do your physicians share a plan to address your needs? Do they recognise the same problems/symptoms?  
• Have tests been duplicated? Why?  
• Are there some services / kinds of help that have been difficult to get? Which ones? Why? |
|                                 | Perceptions of consistency of care and extent to which physicians share common understanding of condition/plan to address the patient’s needs |                                                                                                                                                             |
| **Concluding questions**        | Suggestions for improvement                                                | • Can you recommend suggestions how to improve health services?  
• Is there anything that is important to you that I haven’t asked about? |
|                                 | Other topics that may not have been covered                                 |                                                                                                                                                             |

Source: Adapted from Miller et al. (2009); Guthrie and Wyke (2006), Waibel et al. (2012b)

Quantitative approaches

In patient surveys on continuity of care, *relational continuity* can be measured by analysing the patients’ perceptions regarding the relationship they establish with the different providers and the stability of the professional team. The most frequently used
measurements to evaluate the doctor-patient relationship, mainly in primary care, are based on patient surveys, whereby patients are asked whether they have a personal or regular doctor (Flocke, 1997; Reid et al., 2002). The duration of the relationship between the professional or the concentration and sequence of care between the different providers are also evaluated as part of relational continuity (Reid et al., 2002; Saultz, 2003).

*Informational and managerial continuity* measures have been developed to a lesser degree. They tend to evaluate the transfer and use of information (Letelier et al., 2010), by asking patients whether their previous medical examinations and records were available when they had to see their health care provider, whether the professional was aware of their previous consultations, whether the medical record was complete and used, and finally whether the problems identified in preceding visits were followed up (Flocke, 1997; Reid et al., 2002).

Two quantitative instruments have been developed to comprehensively evaluate the three types of continuity of care and their dimensions, which are applicable across care levels and are aimed at the general population (Table 7):

- The objective of the *Continuity of Care between Care Levels Questionnaire (CCAENA)*, developed and validated in the Catalan context, is to comprehensively evaluate patients’ experiences of continuity of care between care levels (Letelier et al., 2010). The first part reconstructs the care trajectory for a specific condition in the previous year for relational continuity and the last three months for informational and managerial continuity. It also identifies the elements of (dis)continuity experienced in the transition between primary care and outpatient, hospital and emergency care. The second section measures the perceptions of continuity of care without any specific timeframe by means of a Likert scale. The scale is divided in five subscales depending on the type and dimension of continuity measured, including information transfer, consistency of care, accessibility between care levels, relationship patient with GP, relationship patient with secondary care professional. Furthermore, the questionnaire collects information about the health user’s sociodemographic characteristics and morbidity (Aller et al., 2010; Aller et al., 2012).
The objective of the *Nijmegen Continuity Questionnaire* (Uijen et al., 2011) is to measure continuity of care as a multidimensional construct from the patient’s perspective across multiple care settings. The tool was developed and tested in the Netherlands by the Radboud University Nijmegen Medical Centre and consists of 28 items within the following three subscales (Uijen et al. 2012): personal continuity: care provider knows me (five items each for two different providers); personal continuity: care provider shows commitment (three items each for two different providers); team/cross-boundary continuity (four items each for three different groups of providers). Items are scored on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with an additional option to choose (‘I do not know’). In a recent study, the validity, discriminative ability, and reliability of the NCQ has been further examined and confirmed being administered to patients with a chronic disease recruited from general practice (n = 145) and hospital outpatient departments (n = 123) (Uijen et al 2012).

Other tools that have been developed to measure continuity of care mainly focus on primary health care, such as the Primary Care Assessment Tool (PCAT) (Shi and Starfield, 2001), or address continuity as a part of quality of care, such as the Consumer Quality Index Continuum of Care (Berendsen et al., 2009).

**Table 7: CCAENA questionnaire and Nijmegen Continuity Questionnaire**

<table>
<thead>
<tr>
<th>Continuity of care types</th>
<th>CCAENA questionnaire (Aller et al. 2011)</th>
<th>Nijmegen Continuity Questionnaire (Uijen et al. 2011)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relational continuity</strong></td>
<td>▪ Same GP/secondary care professional consulted in last year&lt;br&gt;▪ Trust in the provider&lt;br&gt;▪ Sense of clinical responsibility&lt;br&gt;▪ Effective patient-provider communication</td>
<td>▪ Care provider knows very well what I believe is important in my care&lt;br&gt;▪ Care provider keeps in contact sufficiently when I see other care providers</td>
</tr>
<tr>
<td><strong>Informational continuity</strong></td>
<td>▪ Knowledge of medical history&lt;br&gt;▪ Supply of timely and adequate information to the patient</td>
<td>▪ Care provider knows my medical history very well&lt;br&gt;▪ Care provider always knows very well what he/she did previously</td>
</tr>
<tr>
<td><strong>Managerial continuity</strong></td>
<td>▪ Coordination between providers&lt;br&gt;▪ Adequate sequence (visit to SC as consequence of a referral from PC and vice versa)</td>
<td>▪ Care providers work together very well&lt;br&gt;▪ Care providers always know very well from each other what they do&lt;br&gt;▪ Care providers are very well informed about each other</td>
</tr>
</tbody>
</table>
2.4 Further resources

Another resource and possible inspiration for the development of measures of care coordination and continuity of care for the Austrian context is the Care Coordination Measures Atlas published by the U.S. Agency for Health Care Research and Quality. The Atlas gives a good overview over available tools for the measurement of both care coordination and continuity of care and their empirical validation (AHRQ, 2010). It aims to bring together in one place different available instruments, thereby helping health service managers and researchers to select the appropriate care coordination measures for their particular problem and context. Most of the measures have been developed and validated in the U.S. context and some recent European developments are not included (such as the CCAENA and Nijmegen continuity questionnaires, see section 2.2), but nevertheless the Atlas provides a rich set of measures and examples of their use.

The Atlas is based on a systematic literature review of available measures and instruments for care coordination, and includes 61 measures of structures, process and intermediate outcomes in ambulatory care coordination mostly for people with (multiple) chronic conditions. The Atlas organises these measures in a two-dimensional framework: first, each measure is categorised in terms of the perspective it takes (patient and caregiver, health care professional and provider, system representative). Second, each measure is categorised according to one or multiple of 14 coordination domains, which aim to characterise the specific activities that “good” care coordination entails (Negotiate responsibility; Communicate; Facilitate Transitions; Assess Needs and Goals, Create a Proactive Plan of Care; Monitor, Follow Up and Respond to Change; Support Self-Management; Link to Community Resources Align Resources with Patient and Population Needs; Teamwork; Home Care Management; Medication Management; IT-Enabled Coordination).

The 61 instruments and measures for care coordination were selected from the literature based on the following criteria: (a) relevance to at least one of the 14 domains; (b) allowing quantification of the degree of coordination (excluding eg textual interview guides); (c) a causal logic model exists between the activities measured and the outcomes desired. The data sources differ between the measures, but
tend to include electronic health record systems, consumer surveys, and databases of administrative claims. Surveys or questionnaires with rating scales often have a summary score assessment of the degree of care coordination.
3. Implications for Austria

In this report we have reviewed and highlighted key findings from the literature on the measurement of care coordination and continuity of care. Here, we discuss implications for scoping an initial strategy for care coordination measurement in Austria in four areas: agreeing the purpose and goals of measurement; defining the scope and perspectives of measurement; choosing the right study design and data source; and making a start.

3.1 Agreeing the purpose and goals of measurement

Performance measurement generally serves two purposes: to inform improvements in service delivery, and to ensure accountability in the use of health care resources (Smith et al., 2009). In designing a measurement strategy for Austria, it will be important to determine which purpose should be the major focus. In a context with diverse interests and a measurement culture that is in its early stages, it may be desirable to frame and communicate measurement as a means for identifying and better understanding potential weaknesses in care coordination. An improvement-oriented approach might help to allay the concerns of those who fear public disclosure of performance measurements.

3.2 Defining the perspective and scope of measurement

We have distinguished care coordination (as seen from the perspective of the health system and health professionals) from continuity of care (care coordination seen from the patient’s perspective). Both perspectives yield important insights and should therefore be included in any measurement strategy. A further issue is whether the measurement scope can be extended to cross-cutting population-based issues or needs to be restricted to a disease-specific focus (eg diabetes). A focus on one condition may be more feasible in the short term, but in the longer term a broader, more holistic patient-centred approach is desirable.
3.3 Choosing the right study design and data source

Choice of study design and data source should be informed by the goals and scope of measurement. For example, while administrative data sets may provide information on levels and types of health service utilisation, they are usually not able to capture subjective assessments of the care process or the results of care in terms of coordination. Factors such as whether patients think their providers clearly explain treatment to them may enable understanding of why some patients cannot self-manage their condition(s). These insights are best captured through patient interviews and surveys. Overall, the following relative advantages and disadvantages of different methods and data sources should be taken into account:

- **Patient surveys** are a reliable method for obtaining information about how patients perceive and experience the care provided (Veillard et al., 2009). In measuring continuity of care, patient surveys are to be preferred over general population surveys, given that the general population may lack experience with actual care provided. Recall bias may, however, distort or limit the amount of information that can be gained from individual patients. Well-defined selection criteria can address recall bias (eg patients who have been seen in primary and secondary care within the last three months).

- **Medical records** can provide complete clinical information, but data retrieval is work intensive, even with electronic records. This is because the analysis of care coordination makes most sense if it combines information across multiple care levels. Furthermore, the usefulness of medical records analysis depends on the accuracy and consistency of clinical coding (Veillard et al. 2009).

- **Routine administrative data** tend to be collected for purposes other than performance measurement (eg provider payment). As a result, potentially important aspects may be missing. Large administrative data sets may help to optimise precision. Yet, as with medical records, their usefulness depends on the accuracy and consistency of documentation (Veillard et al., 2009). To obtain a genuinely rounded picture of the degree of care coordination, structures, processes and outcomes should ideally be measured over the entire care cycle. This could be achieved by using available population-based national and/or local data sets to
identify a pathway, or through the linkage of different sets of patient records by an authorised agency (Jonas et al., 2012) in order to move towards a unified information system.

- **Qualitative methods** may be more appropriate when investigators are ‘opening up’ a new field of study or are primarily concerned with identifying and conceptualising salient issues (Fitzpatrick and Boulton, 1994). The following qualitative techniques or study designs may be relevant for Austria when aiming to conduct an analysis within a relatively short period of time (see also the recommendations of the LSE-IHS Implementation Report).

- **In-depth interviews and focus groups with patients, health professionals and managers.** These qualitative data collection techniques are used to gain an insight into informants’ perceptions and experiences of care coordination and continuity of care, facilitating and hampering factors and their relevance. Qualitative research could therefore help to identify and better understand problems in current service delivery and identify improvement strategies.

- **Case studies.** By using this research approach, care integration can be understood in a multifaceted manner (DePoy and Gitlin, 1994). Different sets of information are usually employed for triangulation of information, including in-depth interviews, records analysis, etc. By selecting specific health care organisations or areas (eg those that have implemented a series of coordination mechanisms), case studies enable an in-depth and comprehensive understanding of barriers and facilitators in light of internal and external contextual factors.

### 3.4 Making a start

It will be important to conduct a baseline assessment to allow assessment of progress over time. A baseline survey conducted across ‘matched populations’ would allow assessment of whether better-coordinated care achieves better outcomes compared to areas in which efforts to improve care coordination have not been introduced (Goodwin et al., 2012). If a controlled before and after design using the same instrument to measure performance before (baseline study) and after changes are introduced is used,
observed differences in performance can be assumed to be due to the intervention (controlled before and after studies help protect against the unmeasured effect of secular trends and sudden changes ie changes resulting from maturation and external factors) (Eccles et al., 2003; Ukoumunne et al., 1999). Before starting the baseline study it will be important to have a clear conceptual framework, to review the research plan for timing and scientific quality, to validate the adopted questionnaire or indicators and to conduct a pilot study.

Different questionnaires for measuring care coordination have been developed and used internationally; however, their scope is often limited: the focus is set on one care level or unit, on one specific disease or on chronic care only. Tools that measure continuity of care mainly focus on primary care, on relational continuity or address continuity as a part of quality of care. Two recent validated questionnaires on continuity of care comprehensively evaluate the three types of continuity of care (relational, informational and managerial) and are applicable across care levels (Nijmegen Continuity Questionnaire; CCAENA Questionnaire).

Available questionnaires (see Table 8) should be used to select relevant questions that respond to the study’s specific research objectives (interfaces/care levels; acute and/or chronic diseases; analysis dimensions) and take into account the Austrian context. Retrieved items should be collected to construct a questionnaire which is then administered in Austria. For analysis of continuity of care, we recommend surveying health care users rather than the general population since they will have experience of the health system. It is also important to survey both acute and chronically ill patients. Finally, the survey should encompass multiple care levels and inclusion criteria for survey participants, such as health care users seen by primary and secondary care professionals in the last three months.

The Bertelsmann Gesundheitsmonitor includes some items relevant to continuity of care (Table 9), which could be considered for Austria. An advantage is that these items have already been validated in a German-speaking country. Nevertheless, it may be worth considering adapting it for use on health care users rather than the general population.
Table 8: Example of questionnaires according to perspective and scope of analysis

<table>
<thead>
<tr>
<th>Perspective Scope</th>
<th>Health system/personnel (care coordination)</th>
<th>Health users (continuity of care)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study population</td>
<td></td>
<td>Gesundheitsmonitor questionnaire 2002(^5) (see Table 2)</td>
</tr>
<tr>
<td>Cross-population</td>
<td></td>
<td>Nijmegen Continuity Questionnaire (Uijen et al. 2011) CCAENA Questionnaire (Aller et al. 2011)</td>
</tr>
<tr>
<td>Patients with acute and/or chronic conditions</td>
<td>Assessment of Chronic Illness Care (ACIC; Bonomi et al., (2002); Cramm et al., (2011, 2012))</td>
<td></td>
</tr>
<tr>
<td>Focus on one care level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care</td>
<td>Primary Care Assessment Tool: provider expanded edition (Starfield 2008)</td>
<td>Primary Care Assessment Tool (PCAT) (Shi and Starfield, 2001)</td>
</tr>
<tr>
<td>Secondary care (inpatient)</td>
<td>ICU Nurse-Physician Questionnaire (Shortell 1991)</td>
<td></td>
</tr>
</tbody>
</table>

Table 9: Extraction of questions for the analysis of continuity of care from the Gesundheitsmonitor 2002

<table>
<thead>
<tr>
<th>Type</th>
<th>Dimension</th>
<th>Example question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relational continuity</td>
<td>Consistency of personnel</td>
<td>10. Wie lange sind Sie schon bei diesem Arzt?</td>
</tr>
<tr>
<td></td>
<td>Established patient-provider relationship</td>
<td>21. Wenn Sie an den letzten Kontakt mit Ihrem Hausarzt denken: Wie intensiv hat Ihnen Ihr Hausarzt zugehört, unabhängig davon, wie beschäftigt er war?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>23. Wie stark hatten Sie beim letzten Kontakt das Gefühl, dass Ihr Hausarzt Ihre Äußerungen über Ihren Gesundheitszustand bzw. über Ihre Krankheit ernst nimmt?</td>
</tr>
<tr>
<td>Managerial continuity</td>
<td>Access to secondary care</td>
<td>47. Fand die Überweisung vom Hausarzt zum Facharzt Ihrer Meinung nach rechtzeitig, zu früh oder zu spät statt?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>50. Wie viele Tage haben Sie beim letzten Mal gewartet, um einen Termin mit diesem Facharzt zu bekommen?</td>
</tr>
<tr>
<td></td>
<td>Consistency of care (duplication of tests)</td>
<td>60. Kam es dabei vor, dass Untersuchungen wie z.B. Blut- oder Röntgenuntersuchungen wiederholt wurden?</td>
</tr>
<tr>
<td>Informational continuity</td>
<td>Information transfer</td>
<td>48. Als Sie den Facharzt, an den Sie überwiesen wurden, zum ersten Mal sahen: Hatte er Ihrer Meinung nach alle notwendigen Informationen über Sie persönlich und über Ihren Gesundheitszustand und die Art Ihrer Behandlung?</td>
</tr>
<tr>
<td></td>
<td>Accumulated knowledge</td>
<td>56. Wie viel weiss dieser Facharzt über Ihre gesundheitliche Entwicklung in den letzten Jahren bzw. Über Ihre Krankengeschichte?</td>
</tr>
</tbody>
</table>

4. References


Appendix A International case studies

This appendix describes recent developments in England, the Netherlands and Catalonia (Spain) regarding the measurement of care coordination. Each case study gives a brief overview of the national policy context and efforts to measure health system performance then discusses efforts to measure unwarranted variations in health care delivery and provides examples of initiatives for care coordination measurement and evaluation.

A.1 England

Policy context

The English National Health Service (NHS) is based on a regional system of planning and purchasing health services across all service sectors (public health, primary care services including dentistry, pharmacy and optometry, community health services, social care, mental health, elective and acute hospital care) (Department of Health, 2006). Integration between health and social care provision has become a major issue of concern (Rosen et al., 2011) and evidence of regional variations in service delivery, cost and outcomes (NHS Right Care, 2010, 2011, 2012) raises questions about weaknesses in care coordination.

In primary care, the Quality and Outcomes Framework (QOF), a voluntary general practice-level scheme to reward and incentivise better clinical outcomes, process and structural quality was introduced in 2004. As of 2010/11, 134 indicators are agreed in a national contract between NHS employers and the British Medical Association (BMA General Practitioners Committee and NHS Employers, 2011). The indicators cover clinical care (records, initial diagnosis, ongoing management of 13 major chronic diseases and risk factors such as obesity and smoking), practice organisation (e.g. record keeping, information to patients, staff training, medicines management) and patient experience (through one indicator related to length of appointment). However, apart from secondary care referrals, there is little focus on transitions between settings. In order to accommodate non-average patients and clinical encounters (e.g. when a medication recommended by clinical guidelines is not prescribed due to contraindications for a particular patient), ‘exception reporting’ is possible (BMA General Practitioners Committee and NHS Employers, 2006, 2011).

Currently, national organisations involved in health system governance (the NHS Commissioning Board) and economic (Monitor) and quality regulation (the Care Quality Commission) are working with the Local Government Association and Public Health England to develop a national policy framework on integrated care. The framework, expected for spring 2013, is intended specify clearly how these organisations will cooperate with each other and the Department of Health to translate commitments on integrated care into tangible benefits for patients and users on the ground (Ham, 2012).

At an individual patient level, concerns have been raised that successful integrated care as experienced by the individual is not well defined (National Voices, 2011), and it
often remains unclear to what extent general quality of care-related questionnaires capture patients' perceptions of actual care integration (Goodwin et al., 2012). The NHS Commissioning Board, the national health authority overseeing health care purchasing in England, has therefore recently made the measurement of patient experience one of its key priorities (Gleave, 2012). Based on research suggesting that only 13% inpatients report being asked for their views and experience, the NHS Commissioning Board, working with other partners, has recognised the need for a common framework to describe different aspects of patient experience, building on NICE quality standards, in combination with relevant “improvement methodology” to ensure that health professionals are capable of interpreting and acting on patient feedback (Gleave, 2012).

**National framework for measuring health system performance**

The Department of Health has experimented with a range of different performance frameworks over the past decade. With the last health reform, which is in a process of implementation since 2010, an overarching NHS Outcomes Framework was developed based on which the National Health Service (NHS) as a whole is held accountable (Department of Health, 2010b). In terms of measuring care coordination and integration, the NHS Outcomes Framework has its limits: it is mainly focused on health care; separate frameworks exist for public health and adult and social care (Department of Health, 2010b). However, by international standards, the NHS Outcomes Framework still reflects a fairly comprehensive attempt to measure health system performance (at a global level), by interlinking measurement across all health care sectors and over five broad performance domains (preventing premature death, enhancing quality of life for people with chronic conditions, helping people to recover, ensuring a positive experience of care, protecting people from avoidable harm).

Based on the overarching framework, scientific quality standards are currently in development for 150 conditions to link broad health system goals to more specific actions. Each standard includes a series of 10 to 15 quality statements defining what constitutes good medical practice. Each quality statement, in turn, is accompanied by quantifiable measures of structure, process and outcome (NICE Guidance, 2012). Figure 1 illustrates the interlinkage of measurement levels from broad performance domains at a national level to increasingly precise indicators that are targeted at local health care payers and providers.

**Identifying unwarranted variations in health care delivery**

Another relevant development with respect to the measurement of care coordination is the NHS Atlases of Variation in Health Care, which are being developed by NHS Right Care (funded by Department of Health) in cooperation with various NHS organisations (NHS Right Care, 2010, 2011, 2012). Although not specifically focused on care coordination, the Atlases implicitly raise questions over possible weaknesses in the coordination of care, by pointing to substantial regional variations in avoidable hospital admissions for COPD, asthma and epilepsy, and adverse outcomes such as diabetes-
related amputations which might have been prevented with timely coordination of care. In some regions, Atlases of Variation have supported local purchasers in framing problems of care coordination, by acting as a stimulus for further investigation of possible weaknesses in care pathways (Schang et al.). So far, both system-wide and theme-specific (eg for diabetes or child care) Atlases of Variation have been published based on routinely available data sets (nationwide hospital episode statistics, population and disease registries). The Atlases are widely disseminated to local purchasers and available as an interactive version online. To make the information more useful and actionable for health service planners and to motivate clinicians and managers to further investigate causes of variation, further options for action are suggested for each indicator (NHS Right Care, 2010, 2011, 2012).

**Identifying care pathways using existing data sets**

At a local level, many innovative approaches to measurement are currently being developed (Jonas et al., 2012). A powerful way to illustrate quality and outcomes across the care continuum for a specific condition may be to identify a pathway using existing data sets (Jonas et al., 2012). Figure 2 provides an example of this approach for COPD services in Westminster, London. The pathway starts with a population-based summary of the prevalence of key risk factors for COPD, including smoking prevalence and age distribution. A second component illustrates the prevalence of COPD as recorded in general practices, and contrasts this with expected (modelled) prevalence rates. Thirdly, care quality interventions provided in general practice are summarised, such as the proportion of patients offered stop smoking advice, the proportion of eligible COPD patients offered pulmonary rehabilitation and COPD patients with medication review in the last 15 months. With regard to secondary care, average length of stay and emergency admissions and readmissions for COPD are summarised. Mortality and years of life lost due to mortality from COPD signal the end of the pathway. Finally, cost issues in terms of oxygen prescribing, overall spend on COPD and disaggregated spend on COPD in primary and secondary care settings are given. Corresponding profiles exist for other regions in England. Profiles are used to inform purchasers about the quality of care along care pathways, and to signal potential weaknesses in the quality of care provided in an accessible one-page format (NHS London Health Programmes, 2011).

**Evaluation of local integrated care pilots**

At a local level, the Department of Health has recently commissioned a comprehensive two-year, real-time evaluation of 16 integrated care pilots in different regions (RAND Europe, 2012). These pilots were aimed at encouraging local experimentation with integrated care. Mostly, the initiatives have focused on specific areas such as older people at risk of hospital admission, structured care for dementia, enhanced discharge planning and better care for people in nursing homes. These initiatives did not include

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more radical options such as large-scale integration of health and social care organisations.

A rather innovative feature in the evaluation strategy was the use of formative elements intended to measure changes in coordination and other effects as the pilots were in the process of being implemented (rather than just measuring effects “before” and “after” implementation). Among others, these formative elements included a structured, free-form questionnaire referred to as a ‘Living Document’, which asked local providers and managers to keep a “log” of changes they were making in their local health economies. Furthermore, the real-time measurement strategy entailed evaluations of team participation in regional events, teleconferences on evaluation matters with sites, and feedback of the central evaluation team on the quantitative data provided by each pilot site.

The published evaluation protocol (Ling et al., 2010) provides additional detail of the methodology employed. Qualitative data were also collected through semi-structured interviews and observation in a smaller selection of six “Deep Dive” sites, in order to obtain a more in-depth understanding of local processes, as well as enabling and hindering factors in the implementation of the pilots. The quantitative component aimed to compare secondary health care utilisation for patients receiving the integrated care pilot interventions in a selected number of pilot regions against a control group, by using routinely available clinical data sets (hospital episode statistics, HES), and to compare experiences of staff and patients before and after the intervention(s). To distinguish the ‘before’ from the ‘after’ for patients, the intervention was assumed to have started at the point when patients were recruited or the date the pilot recorded an individual patient as having received an intervention (as opposed to the start of funding or recruitment of staff, etc.), while the ‘after’ date was broadly defined as one year later. However, although the evaluation covered a three-year period, the long-term nature of implementing integrated care means that this timeframe may have been too short to trace effects in some pilots. In particular, because of delays in many pilots starting up, the available time frame may have been not long enough for the full effects of the intervention to be experienced by patients and staff (RAND Europe, 2012).
Figure A1 England: performance measurement framework

<table>
<thead>
<tr>
<th>Domains</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Domain 1:</td>
<td>Preventing premature death</td>
</tr>
<tr>
<td>Domain 2:</td>
<td>Enhancing quality of life for people with long-term conditions</td>
</tr>
<tr>
<td>Domain 3:</td>
<td>Helping people to recover</td>
</tr>
<tr>
<td>Domain 4:</td>
<td>Ensuring that people have a positive experience of care</td>
</tr>
<tr>
<td>Domain 5:</td>
<td>Protecting people from avoidable harm</td>
</tr>
</tbody>
</table>

**Examples of currently existing Quality Standards:**
- Dementia (QS1)
- Stroke (QS2)
- Diabetes in adults (QS6)
- Depression in adults (QS8)
- Chronic heart failure (QS9)
- Chronic obstructive pulmonary disease (COPD) (QS10)
- Alcohol dependence and harmful alcohol use (QS11)
- Breast cancer (QS12)
- End of life care for adults (QS13)
- Service user experience in adult mental health (QS14)
- Patient experience in adult NHS services (QS15)
- Hip fracture in adults (QS16)

**Example:**
- **Quality Standard 6, Diabetes in adults**
  - **Statement 3.** People with diabetes participate in annual care planning which leads to documented agreed goals and an action plan.
  - **Statement 4.** People with diabetes agree with their health care professional a documented personalised HbA\(_1c\) target, usually between 48 mmol/mol and 58 mmol/mol (6.5% and 7.5%), and receive an ongoing review of treatment to minimise hypoglycaemia.
  - **Statement 9.** People with diabetes are assessed for psychological problems, which are then managed appropriately.
  - **Statement 11.** People with diabetes with a foot problem requiring urgent medical attention are referred to and treated by a multidisciplinary foot care team within 24 hours.

Each Quality Standard is accompanied by 10 to 15 Quality Statements how care ought to be provided.

**Example:**
- **Statement 11, People with diabetes with a foot problem requiring urgent medical attention are referred to and treated by a multidisciplinary foot care team within 24 hours.**
  - **Structure:** Evidence of local arrangements to ensure that people with diabetes with a foot problem requiring urgent medical attention are treated by a multidisciplinary foot care team within 24 hours.
  - **Process:**
    - a) Proportion of people with diabetes with a foot problem requiring urgent medical attention referred to and treated by a multidisciplinary foot care team within 24 hours.
    - **Numerator** – the number of people in the denominator referred to and treated by a multidisciplinary foot care team in 24 hours.
    - **Denominator** – the number of people with diabetes with a foot problem requiring urgent medical attention.
    - b) Proportion of people with diabetes with a foot problem requiring urgent medical attention referred to a multidisciplinary foot care team who are treated in accordance with NICE guidance.
    - **Numerator** – the number of people in the denominator treated in accordance with NICE guidance.
    - **Denominator** – the number of people with diabetes with a foot problem requiring urgent medical attention referred to a multidisciplinary foot care team.
  - **Outcome:** Rates of lower limb amputation.

Sources: adapted from (Department of Health, 2010b; NICE Guidance, 2012)

Abbreviations: NHS - National Health Service, NICE – National Institute for Health and Clinical Excellence, QS – Quality Standard
Figure A2 England: identifying care pathways for chronic pulmonary obstructive disease (COPD) in Westminster (compared to London and England)

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Local Number</th>
<th>Local Value</th>
<th>Lon Avg</th>
<th>Eng Avg</th>
<th>Eng Worst</th>
<th>England Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults who smoke</td>
<td>n/a</td>
<td>22.5</td>
<td>20.6</td>
<td>22.2</td>
<td>35.2</td>
<td>10.2</td>
</tr>
<tr>
<td>Population aged 35yrs and over</td>
<td>117,321</td>
<td>47.8</td>
<td>49.9</td>
<td>56.2</td>
<td>37.8</td>
<td>70.4</td>
</tr>
<tr>
<td>Population aged 75yrs and over</td>
<td>12,985</td>
<td>5.2</td>
<td>5.6</td>
<td>7.8</td>
<td>16.6</td>
<td>3.4</td>
</tr>
<tr>
<td>COPD prevalence, recorded</td>
<td>1,971</td>
<td>0.8</td>
<td>1.0</td>
<td>1.6</td>
<td>3.3</td>
<td>0.7</td>
</tr>
<tr>
<td>COPD prevalence, modelled</td>
<td>7,955</td>
<td>3.6</td>
<td>3.9</td>
<td>3.6</td>
<td>6.1</td>
<td>1.9</td>
</tr>
<tr>
<td>COPD prevalence, modelled v. recorded</td>
<td>3.6</td>
<td>4.6</td>
<td>3.9</td>
<td>2.4</td>
<td>6.2</td>
<td>1.3</td>
</tr>
<tr>
<td>Asthma prevalence, recorded</td>
<td>6,725</td>
<td>3.5</td>
<td>5.7</td>
<td>9.1</td>
<td>5.2</td>
<td>3.5</td>
</tr>
<tr>
<td>COPD diagnosis confirmed by post bronchodilator spirometry</td>
<td>314</td>
<td>83.1</td>
<td>80.5</td>
<td>90.3</td>
<td>82.8</td>
<td>24.8</td>
</tr>
<tr>
<td>Exception rate for COPD indicators</td>
<td>999</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>Adults with COPD who smoke</td>
<td>3,960</td>
<td>94.8</td>
<td>95.3</td>
<td>95.2</td>
<td>93.9</td>
<td>97.4</td>
</tr>
<tr>
<td>Patients with long-term conditions with smoking status recorded</td>
<td>3,960</td>
<td>94.8</td>
<td>95.3</td>
<td>95.2</td>
<td>93.9</td>
<td>97.2</td>
</tr>
<tr>
<td>Patients with long-term conditions offered stop smoking advice</td>
<td>6,980</td>
<td>91.9</td>
<td>92.7</td>
<td>92.8</td>
<td>88.9</td>
<td>96.7</td>
</tr>
<tr>
<td>Exception rate for smoking indicators</td>
<td>3,24</td>
<td>0.8</td>
<td>0.8</td>
<td>0.8</td>
<td>0.7</td>
<td>1.4</td>
</tr>
<tr>
<td>Successful smoking quitters at 4 weeks, CO validated</td>
<td>1,270</td>
<td>592</td>
<td>600</td>
<td>614</td>
<td>51</td>
<td>1,454</td>
</tr>
<tr>
<td>Prescribed nicotine replacement therapy (NRT)</td>
<td>4,926</td>
<td>2,015</td>
<td>2,184</td>
<td>2,957</td>
<td>143</td>
<td>10,887</td>
</tr>
<tr>
<td>Prescribed budesonide</td>
<td>1,357</td>
<td>590</td>
<td>984</td>
<td>1,704</td>
<td>275</td>
<td>5,221</td>
</tr>
<tr>
<td>Eligible COPD patients offered pulmonary rehabilitation</td>
<td>999</td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
<td>0.2</td>
<td>0.1</td>
</tr>
<tr>
<td>COPD patients with medical review in last 15 months</td>
<td>1,447</td>
<td>89.7</td>
<td>89.6</td>
<td>89.9</td>
<td>80.7</td>
<td>93.9</td>
</tr>
<tr>
<td>Length of stay, emergency inpatient COPD admissions</td>
<td>1,837</td>
<td>5.9</td>
<td>6.7</td>
<td>6.8</td>
<td>9.8</td>
<td>9.8</td>
</tr>
<tr>
<td>Emergency admissions for COPD, overall</td>
<td>292</td>
<td>1.8</td>
<td>1.9</td>
<td>1.8</td>
<td>4.9</td>
<td>9.9</td>
</tr>
<tr>
<td>Emergency admissions for COPD, COPD registered patients</td>
<td>321</td>
<td>13.6</td>
<td>13.6</td>
<td>12.5</td>
<td>17.9</td>
<td>9.9</td>
</tr>
<tr>
<td>Emergency readmissions within 28 days, overall</td>
<td>91</td>
<td>43.5</td>
<td>41.7</td>
<td>39.6</td>
<td>52.2</td>
<td>25.9</td>
</tr>
<tr>
<td>Emergency readmissions within 90 days, COPD admitted patients</td>
<td>81</td>
<td>43.5</td>
<td>41.7</td>
<td>39.6</td>
<td>52.2</td>
<td>25.9</td>
</tr>
<tr>
<td>Deaths from COPD, all ages</td>
<td>126</td>
<td>15.6</td>
<td>24.2</td>
<td>24.2</td>
<td>40.7</td>
<td>11.3</td>
</tr>
<tr>
<td>Deaths from COPD, &lt;75yrs</td>
<td>40</td>
<td>7.2</td>
<td>11.4</td>
<td>11.8</td>
<td>27.5</td>
<td>3.4</td>
</tr>
<tr>
<td>Years of life lost due to mortality from COPD</td>
<td>40</td>
<td>6.1</td>
<td>9.8</td>
<td>10.5</td>
<td>26.0</td>
<td>1.2</td>
</tr>
<tr>
<td>Deaths with any mention of respiratory disease as cause</td>
<td>955</td>
<td>29.4</td>
<td>33.1</td>
<td>39.9</td>
<td>41</td>
<td>25.7</td>
</tr>
<tr>
<td>Respiratory deaths at own residence</td>
<td>64</td>
<td>16.7</td>
<td>12.9</td>
<td>13.7</td>
<td>7.5</td>
<td>29</td>
</tr>
<tr>
<td>Cost of oxygen prescribing</td>
<td>30</td>
<td>3,005</td>
<td>13.9</td>
<td>10.9</td>
<td>13.1</td>
<td>24.5</td>
</tr>
<tr>
<td>Primary care spend on obstructive airways disease</td>
<td>905,673</td>
<td>2.5</td>
<td>4.1</td>
<td>5.4</td>
<td>13.8</td>
<td>29.1</td>
</tr>
<tr>
<td>Secondary care spend on obstructive airways disease*</td>
<td>2,684,327</td>
<td>11.3</td>
<td>6.6</td>
<td>7.6</td>
<td>16.4</td>
<td>1.9</td>
</tr>
</tbody>
</table>

1 % adults, modelled estimate using Health Survey for England 2006-2008 (APHO Health Profiles). 2-3 % residents, 2008 midyear estimates (ONS). 4 % GP patients on COPD register 2009/10 (QOF). 5 % aged 16yrs+ 2010 (ERPHO). 6 Ratio of modelled 2010 (ERPHO) to recorded prevalence 2009/10 (QOF). 7 % GP patients on asthma register 2009/10 (QOF). 8 % GP patients on COPD register 2009/10 (QOF). 9 No. GP patients excepted from all QOF COPD indicators as a % of all QOF COPD indicator denominators + exceptions 2009/10 (APHO GP Profiles). 10 % GP patients on COPD register (data not currently collected). 11-12 % GP patients on smoking register recorded in last 15 months 2009/10 (QOF). 13 No. GP patients excepted from all QOF smoking indicators as a % of all QOF smoking indicator denominators + exceptions 2009/10 (APHO GP Profiles). 14 Crude rate per 100,000 ONS midyear population estimate 2009/10 (NHS IC). 15-16 Prescribed items per 100,000 ONS midyear population estimate 2009/10 (ePACT). 17 % MRC3+ patients (data not currently collected). 18 % GP patients on smoking register 2009/10 (QOF). 19 Total no. and standardised average no. of days spent in hospital 2009/10 (NHS Comparators). 20 Rate per 1,000 GP registered population 2009/10 (NHS Comparators). 21 % GP patients on COPD register 2009/10 (ERPHO). 22 % all COPD discharges 2009/10 (NHS Comparators, under revision). 23 % patients admitted with COPD as an emergency 2009 (London Health Programmes). 24-26 Directly age-standardised rate per 100,000 European standard population 2007-2009 (NCHOD). 27 % all deaths 2007-2009 (NEoLCIN Profiles). 28 % all respiratory deaths 2007-2009 (NEoLCIN Profiles). 29 £ per head of population (data not currently collected). 30-32 £ per weighted head of population 2009/10 (DH).

A.2 The Netherlands

Policy context

Since the introduction of regulated competition in statutory health insurance in the early 1990s and the introduction of universal health coverage in 2006, the Dutch government has placed increasing emphasis on stimulating innovative models of care which are based on contractual relationships between health insurers and local provider groups. In the care of patients with chronic illnesses in particular, a number of initiatives have been developed. Changes included the launch of disease management programmes based on multidisciplinary cooperation, which were aimed at improving the quality and coordination of care and to ensure affordable costs (de Bakker et al., 2012; Tsiachristas et al., 2011). To accelerate the implementation of long-term disease management, the Dutch Ministry of Health, Welfare and Sport developed a new pricing model called ‘bundled payments’, which enables health insurers to contract all the necessary services for a disease management programme as a single package. In 2007, groups of affiliated health care providers (‘care groups’) started working with bundled payment arrangements for diabetes on an experimental basis, later the model was extended also to COPD (Chronic Obstructive Pulmonary Diseases) and vascular risk management. By 2010, about one hundred care groups were offering diabetes management programmes (Struijs et al., 2012).

National framework for measuring health system performance

In order to trace system-level developments since the 2006 health care reform, the Dutch National Institute for Public Health and the Environment (RIVM) publishes a performance report every two years on behalf of the Ministry of Health. So far, three reports have been published (Westert et al., 2008; Westert et al., 2010; Westert and Verkleij, 2006). The reports draw on information from statistics and available research to provide a summary of major elements of health system performance. The conceptual framework distinguishes three system goals, for which the Ministry of Health is responsible: quality of care, access to care, and affordability. The three system goals are further sub-divided into 13 indicator domains, one of which is care coordination which contains the following seven indicators (Westert et al., 2010: p.86f.):

- First experiences of care groups with bundled payment
- Extent to which patients have to repeat their story to different health care providers
- Patient experiences with health care providers giving contradictory information
- Percentage of chronically ill people who experienced coordination problems with medical tests
- Supply of support and information at hospital discharge
- Number of health care providers connected to the National Exchange Point of Electronic Health Records
Percentage of hospitals where information on medication prescribed in hospital and elsewhere is electronically accessible on hospital wards and elsewhere

In total, the 13 indicator domains comprise 125 indicators and key findings for each indicator based on (international) literature (Arah et al., 2006). Health care is divided into four specific health care needs: staying healthy (prevention), getting better (cure), living independently with a chronic illness or disability (long-term care), and end-of-life care. For each care demand, health care performance is analysed for quality, accessibility and affordability. The indicator framework is well accepted internationally and has been adopted by the Organisation for Economic Co-operation and Development (OECD) for the further development of international comparisons of health system performance (OECD, 2009).

Identifying unwarranted variations in health care delivery

Similar to many other countries, there is an increasing recognition in the Netherlands that, in order to improve performance of the health system in general and care coordination in particular, analysis of regional variations in health care delivery provides an important lever for action targeted at specific care deficits. An Atlas that specifically focuses on variations in quality of care is currently in development. The reason for developing this Dutch Atlas of Health Care Variation is related to the aim of tracing effects of the 2006 Health Care Reform, by using systematic measurement to ensure and promote transparency in the health system (Westert, 2012). This Atlas is commissioned by the Dutch health insurers’ association. At the time of writing (November 2012), the Atlas is available as a prototype (Zorgverzekeraars Nederland, 2011). Furthermore, there is a Dutch National Atlas of Public Health, which is commissioned by the Dutch Ministry of Health (VWS) and developed by the National Institute of Public Health and the Environment (RIVM). This web-based Atlas maps regional distribution of broader health-related issues such as vaccinations and obesity, and is up-dated four times a year using statistical databases. The Atlas targets governmental policy advisers, municipal staff, but also seeks to provide health insurers, providers and the public with a visual tool and accessible information about health and the health system (RIVM, 2012).

National minimum data set for measuring quality of integrated care at a care group level

In relation to bundled payments, the Health Care Inspectorate (IGZ) has defined a national level minimum data set through its Visible Care programme (Zichtbare Zorg)

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7 Atlases of Variation have also been developed in England (NHS Right Care, 2010, 2011, 2012), the U.S. (The Dartmouth Institute for Health Policy and Clinical Practice, 2012), Germany by an independent foundation (Nolting et al., 2011) and by the scientific institute of SHI physicians’ associations (ZI, 2012), and Spain by a partnership of academic and governmental institutions (Grupo Atlas VPM, 2011).
to provide a common measurement framework across all regions. The data set is based on existing clinical guidelines and protocols, and seeks to provide measures of health care quality in terms of structure, process and outcome performance. The indicator set includes disease-specific performance indicators, such as those relating to intermediate outcome measures for patients with COPD, diabetes or cardiovascular disease, but also broader cross-cutting indicators, which seek to capture the smoothness of a patient’s journey over time and across settings (Zichtbare Zorg, 2011). In relation to the quality of integrated care, the minimum data set requires providers to report the following two indicators (Tsiachristas et al., 2011; Zichtbare Zorg, 2011):

- % patients with an individual care plan
- % patients assigned to a central health care provider.

Good performance measurement with respect to the degree of integrated care is considered essential to support negotiations between health care purchasers and providers and facilitate regulated competition (Tsiachristas et al., 2011). Therefore, following an initial period of voluntary reporting of these performance indicators by the care groups to IGZ, the governance framework for these indicators has now been made mandatory for care groups of providers who wish to contract with health insurers for bundled payments and disease management. Since 2009, legislative requirements exist for insurers and providers of care to report on this minimum data set (Zichtbare Zorg, 2011). Care groups of affiliated providers, who tend to be led and owned by general practitioners (GPs), but may also involve other health professions, also play a crucial role in mediating relationships to practising local physicians. At a local care group level, reflective feedback data has also been fundamental in fostering transparency about the quality of integrated care delivered. As a recent evaluation suggests (Struijs et al., 2012), care groups have started to use performance information to provide their individual health care providers with periodic reflective information about their work, to formulate improvement targets, and to offer providers individual support, for instance by offering additional training for practice nurses.

**Evaluation of three years of bundled payments for diabetes care**

A nationwide evaluation of bundled care payments has just been published (Struijs et al., 2012). The evaluation was based on three main methods for data collection: (1) patient record systems of health care providers, (2) patient questionnaires and (3) semi-structured interviews with stakeholders. Patient record systems of health care providers contained information on patient characteristics (such as age and gender), check-ups and tests performed (such as the yearly HbA1c tests) and clinical outcome measures (such as blood pressure) and were used to follow-up patients who were under the care of the care group for the study period of two years.

Patient questionnaires consisted of existing scales designed to assess the coordination of the care delivered and patient health, quality of life and lifestyle in integrated long-term health care. In particular, the Patient Assessment of Chronic Illness Care (PACIC) that has been developed in the United States and validated for the Netherlands (Vrijhoef et al., 2009) was used to evaluate how well the elements of the Chronic Care
The Chronic Care Model consists of six closely related components: (1) the health care system, (2) the community, (3) self-management support, (4) decision support, (5) delivery system design and (6) clinical information systems.
A.3 Spain, with a focus on the autonomous region of Catalonia

Policy context

The distinct regional services that comprise the decentralised Spanish National Health System have developed a number of experiences to improve care integration and collaboration among the providers involved in the health care process, eg chronic diseases programs in the Basque Country or integrated health care providers in Catalonia (Vázquez 2012). The devolution of public health competences to autonomous communities since the early 1980s (García-Armesto et al., 2010) also raised the need for investigating regional health system performance, and focusing more in depth on similarities and differences as a basis for stimulating learning between the regions. This case study will first highlight a national perspective on identifying unwarranted variations in health care delivery, and will subsequently provide a more in-depth account of Catalonia (García-Armesto et al., 2010). The Catalan case provides a particularly insightful example into the analysis and measurement of the performance of integrated health care networks.

Identifying unwarranted variations in health care delivery

To investigate the quality of care at national and regional levels, 18 national and regional Health care Authorities in Spain have initiated the Atlas VPM programme to examine variations in medical practice (Grupo Atlas VPM, 2008). Atlas VPM involves two methodological approaches: first, an examination of geographic population-based variations in health service utilisation and performance, to examine the extent to which the place where people live influences their access to and utilisation of effective and safe care, by exploring social and supply-sensitive variations in performance. Second, a hospital-specific perspective is adopted in analysing whether health care quality is influenced by the providers that treat a person (Grupo Atlas VPM, 2008). To analyse these questions, hospital discharge claim data and the national survey for hospital information are used. So far, theme-specific Atlases have been published on regional variations in areas such as paediatric care, cardiovascular care, mental health and avoidable hospitalisations (Grupo Atlas VPM, 2011). Furthermore, Atlas VPM offers a website and web-based analytic tools, and also seeks to translate knowledge into practice through various accessible flyers, policy summaries and meetings with decision-makers.9

9 For more information see http://www.atlasvpm.org/avpm/
The development of integrated health care networks (IHNs) has received attention in various countries (Amelung et al., 2009). The Catalan health system is characterised by a purchaser-provider split. Care is provided by a number of contracted providers: on the one hand, a public company, the Catalan Health Institute, and on the other, consortia, municipal foundations and private foundations (mainly non-profit but also for-profit) (Decree of the integrated public healthcare system of Catalonia (SISCAT), 2010). The presence of a number of independent providers influenced the emergence of integrated health care networks (IHNs) which attempt to provide joint management of primary, secondary or specialist and long-term care (García-Armesto et al., 2010; Vázquez and Vargas, 2009). IHNs use various strategies to provide a coordinated continuum of services to a defined population and are willing to be held clinically and fiscally accountable for the outcomes and health status of the population (Shortell 2000). In Catalonia, different efforts have been made to analyse care integration within IHNs. First, a framework was developed for the analysis of the IHN performance and applied in different contexts. Second, the CCAENA questionnaire was developed, validated and administrated to Catalan health care users. And finally, a set of care coordination indicators were elaborated and are currently validated in the Catalan National Health Service.

Analysis of the performance of integrated health care networks

A conceptual framework for the analysis of IHNs has been developed by Vázquez and Vargas (2009) based on a review of the literature published between 1983 and 2007 to analyse the performance of IHNs in the Catalan context. The framework takes into account the internal processes developed by an IHN to achieve its objectives, and the context in which an IHN performs (Figure 3). Internal processes refer to several organisational elements that are critical for care integration to exist, e.g., an organic structure with mechanisms that enable efficient communication between different health professionals (Longest and Young, 2000), a common culture and leadership with values oriented toward teamwork, collaboration, and performance (Kornaki and Silversin, 1998) or an internal resource allocation system that aligns the incentives of health services to the global objectives of the network (Shortell et al., 1994). Contextual elements embrace policy goals and strategies, public insurance characteristics (sources, benefit packages, and access conditions) or funding allocation methods (Vázquez 2005). The analysis of IHN intermediate outcomes (care coordination, continuity of care and access) and final outcomes (equity of access, efficiency and quality of care) are further included in the framework.

The analysis of IHN performance builds on qualitative and quantitative methods of data collection, depending on the analysis domain (context, process, intermediate and final outcome). For the analysis of the context and internal processes a document analysis of policy documents, legislation, and organisation charts, etc. is suggested. Different methods and tools can be used for the analysis of intermediate and final outcomes, including individual interviews and focus groups with health professionals and managers for the analysis of care coordination and access, or user’s case studies or surveys with health care users for the analysis of continuity of care. The final outcomes
can be measured by employing surveys to health care users (equity of access) or by means of records analysis of clinical, administrative and institutional fiscal records (efficiency) (Vázquez and Vargas 2009; Vázquez et al. 2009). Although the framework has been developed for the analysis of IHN performance measurement, it can be also applied when targeting to understand care integration and underlying causes within or across selected health care organisations or areas; however, in any case, the framework needs to be adapted to the particular context and evaluation objectives (Vázquez and Vargas 2009).

The framework for the analysis of IHN performance has been used in various projects on the regional level (Catalonia) and on the international level (in Columbia and Brazil within the Equity-LA project10 and will be used in the Equity-LA II project). In Catalonia, the Consortium for Health care and Social Services of Catalonia (CSC), a public entity that groups public health providers of the Catalan national health system, has carried out different studies to analyse integration in health care and its implication for care coordination, continuity, quality, access and efficiency. First, a multiple case study of six IHNs was conducted to determine how contextual elements and internal processes influence integrated care (Vázquez and Vargas 2009). In a further step, the intermediate outcomes of IHN were analysed; both from the provider’s perspective (health professionals and IHN managers) to analyse care coordination by means of in-depth interviews (Henao et al., 2009; Vargas and Vázquez, 2007), and from the patient’s perspective to analyse continuity of care by employing a multiple-case study design (Waibel et al., 2012b).

**Quantitative measures of continuity of care and care coordination in Catalonia**

Recently, the analysis of the impact of care integration has been amplified by the development, validation and application of a questionnaire to Catalan health care users (see explanation of CCAENA in section 2.2). The CCAENA questionnaire aims to comprehensively evaluate patients’ experiences of continuity of care between care levels (Aller et al., 2012). In a first step, the questionnaire was developed and validated (Aller et al., 2012). In a second step, a cross-sectional study was carried out by means of a survey of users of the Catalan public health care system in three selected areas to explore the potential influence of health care factors on continuity of care experiences, specifically the different management models for primary and secondary care levels. 1500 face-to-face interviews were conducted with patients of 18 years of age or over who had received primary and secondary care for the same condition in the three months prior to the survey. This approach permitted measuring the degree of continuity of care perceived by health care users (Aller 2010) as well as analysing the organisational, contextual and socio-economic factors influencing their perceptions of continuity of care (Aller 2012).

Currently, a set of care coordination indicators across care levels are validated in the Catalan National Health Service. 47 indicators were identified by means of a literature review in different databases (Medline, ISI Web of Knowledge, EBSCO, BIREME and

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10 Equity-LA project: http://www.equity-la.eu/
others) and were then reduced to 34 indicators within two expert panels. The selected set of indicators include five structural and nine process indicators of informational coordination, 17 process indicators of managerial care coordination and three outcome indicators of general care coordination. During the on-going validation process, reliability and feasibility of the indicator (availability of necessary data for the calculation of the indicator), costs and effort of the data collection are evaluated. The final set of indicators will be applied in three different Catalan health care environments to measure care coordination across care levels.

Figure A3: Framework for analysing integrated health care organisations and their outcomes

![Framework for analysing integrated health care organisations and their outcomes](image)

Source: Vázquez and Vargas (2009) and Vargas et al. (2011)

11 The report on the distraction and preselection of the care coordination indicators will be available at: http://www.consortci.org/publicacions/cataleg-de-publicacions/instruments
## Appendix B Performance indicators

### Table B1: Performance indicator types and their strengths and limitations

Sources: (Davies, 2005; McGlynn, 1998; Smith et al., 2009)

<table>
<thead>
<tr>
<th>Indicator type</th>
<th>Strengths</th>
<th>Limitations</th>
</tr>
</thead>
</table>
| **Structure**  | Expedient: Data often available  
Efficient: one indicator may relate to several processes and outcomes  
Relatively inexpensive  
Particularly useful as markers of aggregate (system) performance | May be less appealing than outcome measures for patients and policy-makers  
Causal relationships between structure and outcomes not always understood  
Not always immediately actionable: eg changes in doctor/nurse ratios may take time |
| **Process**    | Easy to interpret when linked to evidence-based care guidelines  
Not subject to time lags  
Usually actionable, by provide clear guidance on what must be remedied to improve health care quality  
Measured readily and unobtrusively, eg via administrative or medical records  
Smaller sample size: can identify significant quality deficiencies with much smaller sample sizes than outcome indicators  
Can capture aspects of care that are valued by patients other than health outcomes (eg speed of access; patient experience) | Salience: May be less appealing than outcome measures for patients and policy-makers unless the link to outcomes can be explained.  
Specificity: care processes are often quite specific to a single disease or single type of medical care therefore process measures across several clinical areas or aspects of service delivery may be required to represent quality for a particular group of patients  
Adverse behaviour: may give rise to gaming and relatively easy manipulation, can become ‘tick box’ exercises for providers  
Focus on process may stifle innovation and the development of new modes of care.  
Usefulness may dissipate as technology and modes of care change |
| **Outcome**    | Focus: direct attention towards the patient (rather than the service) and supports a ‘whole system’ perspective  
Meaningful: measure what matters to patients and policy-makers  
Reflect all processes and structures of care  
Most useful when established causal links exist between structure, process and outcome  
Not easily manipulated, although providers can influence risk-adjusted outcomes by exaggerating the severity of patients’ conditions (upstaging)  
So far effectively applied in surgery, eg cardiac surgery  
May encourage providers to invest in strategies that may lead to longer-term benefits (eg health promotion)  
Measurement definition: some outcome aspects can be measured validly and reliably (eg death) | Potential for risk selection among providers, if linked to eg incentives and/or public reporting  
Time lag between care and outcome  
Measurement definition: some outcome aspects are notoriously difficult to measure (eg wound infection)  
Attribution: may be influenced by many factors outside the control of a health care system or provider organisation  
Sample size: requires large sample sizes to detect a statistically significant effect even when there are manifest problems with the processes of care.  
Interpretation: may be difficult to interpret if the processes that produced them are complex or occurred distant to the observed outcome.  
Ambiguity: good outcomes can often be achieved despite poor processes of care (and vice versa). |
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<tr>
<td><strong>Incentives for care coordination</strong></td>
<td>* Arrangements to provide care target the promotion of cooperation among providers as an explicit objective &lt;br&gt; * Arrangements to provide and pay for care include stipulations regarding quality goals &lt;br&gt; * Payers selectively contract with providers on the basis of their capacity to coordinate care/to provide coordinated care &lt;br&gt; * Primary care physicians receive incentive payments &lt;br&gt; * Care coordinators receive a budget</td>
<td>OECD questionnaire on coordination of care 2006 (Oxley, 2010)</td>
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<tr>
<td><strong>Service-specific availability</strong></td>
<td>* Number of facilities that offer specific services (for chronic care, eg foot checks, eye exams) relative to the total number of facilities &lt;br&gt; * Number of facilities that offer specific services (for chronic care, eg foot checks, eye exams) relative to the total population in the same geographical area</td>
<td>WHO Handbook of Indicators and their Measurement Strategies (WHO, 2010)</td>
</tr>
<tr>
<td><strong>Summary score: service-specific readiness</strong></td>
<td>* Capacity of health facilities to provide a specific service, measured through the presence of tracer items that may include trained staff, guidelines, equipment/supplies, diagnostic capacity, medicines and commodities for coordinated chronic care &lt;br&gt; * Cumulative availability of components required in health facilities to deliver specific services, where an overall score for a specific service may be calculated as the weighted or unweighted average of a number of items relative to the total number of items in that service</td>
<td>WHO Handbook of Indicators and their Measurement Strategies (WHO, 2010)</td>
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<tr>
<td><strong>Care protocols and pathways</strong></td>
<td>* Availability of structured patient pathways that define who should do what, when, in which timeframe, including when to refer the patient to another specialist, physiotherapist etc. &lt;br&gt; * Percentage of eligible patients with a care plan</td>
<td>Model of measurement of structural integration (Ahgren and Axelsson, 2005)</td>
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<tr>
<td><strong>Structured medical documentation</strong></td>
<td>* Percent of practices and hospitals which record medical history, diagnoses, treatments and patient-relevant information (eg allergies) to ensure information continuity over time and across providers</td>
<td>Quality and Outcomes Framework, England (BMA General Practitioners Committee and NHS Employers, 2011)</td>
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<tr>
<td><strong>Disease registries at practice level</strong></td>
<td>* Percent of practices able to produce a register of patients eg with diabetes, COPD, asthma,</td>
<td>Quality and Outcomes Framework, England (BMA General Practitioners Committee and NHS Employers, 2011)</td>
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<tr>
<td><strong>Multidisciplinary teams</strong></td>
<td>* Availability of teams eg consisting of generalists, nurses, neurologists, renal to provide complex care to diabetes patients</td>
<td>Model of measurement of structural integration (Ahgren and Axelsson, 2005)</td>
</tr>
<tr>
<td><strong>Physician continuing education</strong></td>
<td>* Percent of physicians who regularly participate in quality circles</td>
<td>Quality assurance in joint institutions of sickness funds and regional associations of SHI physicians in German disease management contracts (Nordrheinische Gemeinsame Einrichtung, 2011)</td>
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<tr>
<td><strong>Patient education and self-management support</strong></td>
<td>* Percent of patients who received disease-specific coaching eg training how to correctly use sprays for COPD and asthma</td>
<td>Quality assurance in joint institutions of sickness funds and regional associations of SHI physicians in German disease management contracts (Nordrheinische Gemeinsame Einrichtung, 2011)</td>
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<td>Reminder systems</td>
<td>* Percent of practices with a system in place to remind patients of follow-up visits</td>
<td>Quality and Outcomes Framework, England (BMA General Practitioners Committee and NHS Employers, 2011)</td>
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| **Timeliness**               | • Proportion of patients who report receiving test results within a specified time period  
• Proportion of patients’ test results communicated between providers (eg with a letter from the hospital to the GP, and vice versa, or electronically through EMR) a specific timeframe  
• For heart attack patients, median time to thrombolytic therapy or percutaneous transluminal coronary angioplasty (PTCA) | Care Coordination Measures Atlas (AHRQ, 2010)  
WHO Handbook of Indicators and their Measurement Strategies (WHO, 2010) |
| **Waiting times and access to care** | • Percent patients who report obtaining after-hours care was somewhat or very difficult  
• Using emergency department in past 2 years  
• Seeing a doctor or nurse the last time they were sick (a) in less than 6 days (b) after 6 days or longer  
• Percent of patients getting access to a specific service or type of provider (eg with general practitioner, specialist, physiotherapist) within a specified time period, based on objectives such as to ensure: access to a primary care professional within 24 hours or a primary care doctor within 48 hours; a maximum four-hour wait in AandE from arrival to admission, transfer or discharge; a maximum 31-day wait for subsequent treatment where the treatment is surgery or an anti-cancer drug regimen | Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011)  
| **Delays in care transfers**   | • Percent of patients who experienced gaps in hospital/surgery discharge planning  
• Number of delays in transfer to other care settings (eg hospital discharge to home, social care) by reason, eg awaiting care package in own home, awaiting residential home placement or availability, awaiting nursing home placement or availability, awaiting public funding, awaiting community equipment and adaptation | Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011)  
National performance reporting in the English NHS (Department of Health, 2012) |
| **Safety Medication continuity** | • Percentage of adults whose provider asks about other prescribed medication  
• Percentage of patients where appropriate medication continues to be prescribed (taken) following transitions between settings (eg ambulatory and hospital)  
• Prescribing rates of ineffective, addictive or harmful drugs (eg benzodiazepines) | Care Coordination Measures Atlas (AHRQ, 2010)  
WHO Handbook of Indicators and their Measurement Strategies (WHO, 2010)  
French general practitioner contract on the improvement of individual practice ("CAPI") (Commission des Comptes de Sécurité sociale, 2011) |
| **Information transfer between settings** | • Proportion of patients having to tell the same story twice/multiple times to different (eg ambulatory, hospital, nursing care) providers  
• Proportion of patients for whom test results/records are not available at appointment or duplicate tests are ordered  
• Proportion of cases where key information was not shared among providers  
• Proportion of cases where specialist lacked medical history or regular doctor not informed about | Dutch Performance Report 2010 (Westert et al., 2010)  
Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011) |
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<td><strong>specialist care</strong></td>
<td>• Proportion of patients who reported regular doctor seemed uninformed about hospital/ surgery care</td>
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| **Provision of key (disease-specific) care services** | • Proportion of patients receiving recommended care according to clinical guidelines, eg in the case of diabetes mellitus type 2:  
  • high proportion of patients receiving nine key care processes based on clinical guidance  
  • high proportion of patients having an annual eye exam  
  • high proportion of patients with annual review kidney function  
  • high proportion of patients receiving antiplatelets in the case of macroangiopathic co-morbidities or secondary disorders  
  • Note: exception reporting may be necessary, as physicians may have good reasons to deviate from guidelines, eg patient refusal, certain co-morbidities | Minimum data set in Dutch bundled payments for chronic care (Zichtbare Zorg, 2011)  
NHS Atlas of Variation in Health Care (NHS Right Care, 2011) based on clinical guidance by the National Institute for Health and Clinical Excellence  
Quality assurance in joint institutions of sickness funds and regional associations of SHI physicians in German disease management contracts (Nordrheinische Gemeinsame Einrichtung, 2011)  
*For more information on exception reporting, see Quality and Outcomes Framework (BMA General Practitioners Committee and NHS Employers, 2011)* |
| **Interdisciplinary cooperation** | • Involvement of multi-disciplinary care teams or other care disciplines as appropriate, eg in the case of diabetes mellitus type 2  
  • proportion of patients with diabetic foot who are co-treated with a specialized facility  
  • proportion of patients referred to an ophthalmologist for regular screening for retinopathy  
  • Note: referral-based indicators do not indicate whether the relevant service was actually provided | Quality assurance in joint institutions of sickness funds and regional associations of SHI physicians in German disease management contracts (Nordrheinische Gemeinsame Einrichtung, 2011) |
| **Relational continuity/ Ongoing patient–provider relationship** | • Percent of patients with a known care provider/ a regular doctor or place of care/ usual source of care  
  • Among patients with complex care needs reporting a regular doctor or place of care, percent reporting that regular doctor or place of care  
  • is accessible  
  • knows them  
  • helps them to coordinate care | Minimum data set in Dutch bundled payments for chronic care (Zichtbare Zorg, 2011)  
Continuity of care indices (Bice and Boxerman, 1977; Roos et al., 1998)  
Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011) |
| **Continual reviews of past care** | • Percent of patients asked to review their medication list during a primary care office visit (eg to check for contra-indications)  
  • Percent of patients who reported pharmacist or doctor did not review prescriptions in past year | Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011) |
<p>| <strong>Integration of public health interventions into primary care</strong> | • Provision of key public health interventions in primary care, eg achievement of a target (eg 75%) vaccination rate for over 65 years old patients | French general practitioner contract on the improvement of individual practice (&quot;CAPE&quot;) (Commission des Comptes de Sécurité sociale, 2011) |</p>
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| **Surrogate/ Clinical/ Physiological parameters** | ▪ Proportion of patients with diabetes with HBA1c values, blood pressure, etc. within a defined (target) range  
▪ Low proportion of patients with high HbA1c levels  
▪ High proportion of patients who have reached their individually agreed HbA1c levels  
▪ Among patients with diabetes, heart disease and/or hypertension who had their blood pressure checked in past year, percent reporting that blood pressure was appropriately controlled the last time checked | Quality assurance in joint institutions of sickness funds and regional associations of SHI physicians in German disease management contracts (Nordrheinische Gemeinsame Einrichtung, 2011)  
Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011) |
| **Avoidable hospital admissions** | ▪ Rate of emergency hospital admissions of patients due to acute exacerbations of their chronic disease (eg COPD, asthma, diabetes)  
▪ Percent of patients admitted to hospital due to medication errors (due to interactions, omissions, ineffective medication, inappropriate medications (where risk of harm exceeds potential benefits) | NHS Atlas of Variation in Health Care (NHS Right Care, 2011) |
| **Serious clinical incidents, sentinel events** | ▪ Proportion of patients with health outcomes which are avoidable given the current state of medical knowledge and access to appropriate care, eg St Vincent indicators in the case of diabetes mellitus type 2  
▪ Proportion of diabetic patients with minor and major amputations  
▪ Proportion of diabetic patients suffering renal failure  
▪ Proportion of diabetic patients going blind | NHS Atlas of Variation in Health Care (NHS Right Care, 2011)  
St Vincent Declaration (WHO Regional Office for Europe and International Diabetes Federation, 1989) |
| **Clinical errors** | ▪ Proportion of patients who experienced medical, medication, or lab error | Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011) |
| **Patient experience of care** | ▪ Percent of patients perceiving their care as well-coordinated  
▪ Percent of respondents who report that doctors or staff at regular place of care spend enough time with them  
▪ encourage questions, explains things clearly  
▪ contact them to see how things are going  
▪ can be called easily to ask a question or get advice engage them in care management for chronic condition | Care Coordination Measures Atlas (AHRQ, 2010); CCAENA questionnaire and Nijmegen Continuity Questionnaire  
Commonwealth Fund international survey of patients with complex care needs (Schoen et al., 2011) |