

## Primary care **Putting people first**



This chapter describes how primary care brings promotion and prevention, cure and care together in a safe, effective and socially productive way at the interface

between the population and the health system. In short, what needs to be done to achieve this is "to put people first": to give balanced consideration to health and wellbeing as well as to the values and capacities of the population and the health workers<sup>1</sup>. The chapter starts by describing features of

## Chapter 3

Good care is about people	42
The distinctive features of primary care	43
Organizing primary-care networks	52
Monitoring progress	56

health care that, along with effectiveness and safety, are essential in ensuring improved health and social outcomes.

These features are person-centredness, comprehensiveness and integration, and continuity of care, with a regular point of entry into the health system, so that it becomes possible to build an enduring relationship of trust between people and their health-care providers. The chapter then defines what this implies for the organization of health-care delivery: the necessary switch from specialized to generalist ambulatory care, with responsibility for a defined population and the ability to coordinate support from hospitals, specialized services and civil society organizations.

#### Good care is about people

Biomedical science is, and should be, at the heart of modern medicine. Yet, as William Osler, one of its founders, pointed out, "it is much more important to know what sort of patient has a disease than what sort of disease a patient has"<sup>2</sup>. Insufficient recognition of the human dimension in health and of the need to tailor the health service's response to the specificity of each community and individual situation represent major shortcomings in contemporary health care, resulting not only in inequity and poor social outcomes, but also diminishing the health outcome returns on the investment in health services.

Putting people first, the focus of service delivery reforms is not a trivial principle. It can require significant - even if often simple - departures from business as usual. The reorganization of a medical centre in Alaska in the United States, accommodating 45 000 patient contacts per year, illustrates how far-reaching the effects can be. The centre functioned to no great satisfaction of either staff or clients until it decided to establish a direct relationship between each individual and family in the community and a specific staff member<sup>3</sup>. The staff were then in a position to know "their" patients' medical history and understand their personal and family situation. People were in a position to get to know and trust their health-care provider: they no longer had to deal with an institution but with their personal caregiver. Complaints about compartmentalized and fragmented services abated<sup>4</sup>. Emergency room visits were reduced by approximately 50% and referrals to specialty care by 30%; waiting times shortened significantly. With fewer "rebound" visits for unresolved health problems, the workload actually decreased and staff job satisfaction improved. Most importantly, people felt that they were being listened to and respected – a key aspect of what people value about health care<sup>5,6</sup>. A slow bureaucratic system was thus transformed into one that is customer-responsive, customerowned and customer-driven<sup>4</sup>.

In a very different setting, the health centres of Ouallam, a rural district in Niger, implemented an equally straightforward reorganization of their way of working in order to put people first. Rather than the traditional morning curative care consultation and specialized afternoon clinics (growth monitoring, family planning, etc.), the full range of services was offered at all times, while the nurses were instructed to engage in an active dialogue with their patients. For example, they no longer waited for women to ask for contraceptives, but informed them, at every contact, about the range of services available. Within a few months, the very low uptake of family planning, previously attributed to cultural constraints, was a thing of the past (Figure  $3.1)^7$ .

People's experiences of care provided by the health system are determined first and foremost by the way they are treated when they experience a problem and look for help: by the responsiveness of the health-worker interface between population



Women attending the health centre (%)





and health services. People value some freedom in choosing a health provider because they want one they can trust and who will attend to them promptly and in an adequate environment, with respect and confidentiality<sup>8</sup>.

Health-care delivery can be made more effective by making it more considerate and convenient, as in Ouallam district. However, primary care is about more than shortening waiting times, adapting opening hours or getting staff to be more polite. Health workers have to care for people throughout the course of their lives, as individuals and as members of a family and a community whose health must be protected and enhanced<sup>9</sup>, and not merely as body parts with symptoms or disorders that require treating<sup>10</sup>.

The service delivery reforms advocated by the PHC movement aim to put people at the centre of health care, so as to make services more effective, efficient and equitable. Health services that do this start from a close and direct relationship between individuals and communities and their caregivers. This, then, provides the basis for person-centredness, continuity, comprehensiveness and integration, which constitute the distinctive features of primary care. Table 3.1 summarizes the differences between primary care and care provided in conventional settings, such as in clinics or hospital outpatient departments, or through the disease control programmes that shape many health services in resource-limited settings. The section that follows reviews these defining features of primary care, and describes how they contribute to better health and social outcomes.

### The distinctive features of primary care

## Effectiveness and safety are not just technical matters

Health care should be effective and safe. Professionals as well as the general public often over-rate the performance of their health services. The emergence of evidence-based medicine in the 1980s has helped to bring the power and discipline of scientific evidence to healthcare decision-making<sup>11</sup>, while still taking into consideration patient values and preferences<sup>12</sup>. Over the last decade, several hundred reviews of

Conventional ambulatory medical care in clinics or outpatient departments	Disease control programmes	People-centred primary care
Focus on illness and cure	Focus on priority diseases	Focus on health needs
Relationship limited to the moment of consultation	Relationship limited to programme implementation	Enduring personal relationship
Episodic curative care	Programme-defined disease control interventions	Comprehensive, continuous and person- centred care
Responsibility limited to effective and safe advice to the patient at the moment of consultation	Responsibility for disease-control targets among the target population	Responsibility for the health of all in the community along the life cycle; responsibility for tackling determinants of ill-health
Users are consumers of the care they purchase	Population groups are targets of disease-control interventions	People are partners in managing their own health and that of their community

effectiveness have been conducted<sup>13</sup>, which have led to better information on the choices available to health practitioners when caring for their patients.

Evidence-based medicine, however, cannot in itself ensure that health care is effective and safe. Growing awareness of the multiple ways in which care may be compromised is contributing to a gradual rise in standards of quality and safety (Box 3.1). Thus far, however, such efforts have concentrated disproportionately on hospital and specialist care, mainly in high- and middleincome countries. The effectiveness and safety of generalist ambulatory care, where most interactions between people and health services take place, has been given much less attention<sup>14</sup>. This is a particularly important issue in the unregulated commercial settings of many developing

# **Box 3.1** Towards a science and culture of improvement: evidence to promote patient safety and better outcomes

The outcome of health care results from the balance between the added value of treatment or intervention, and the harm it causes to the patient<sup>16</sup>. Until recently, the extent of such harm has been underestimated. In industrialized countries, approximately 1 in 10 patients suffers harm caused by avoidable adverse events while receiving care<sup>17</sup>: up to 98 000 deaths per year are caused by such events in the United States alone<sup>18</sup>. Multiple factors contribute to this situation<sup>19</sup>, ranging from systemic faults to problems of competence, social pressure on patients to undergo risky procedures, to incorrect technology usage<sup>20</sup>. For example, almost 40% of the 16 billion injections administered worldwide each year are given with syringes and needles that are reused without sterilization<sup>14</sup>. Each year, unsafe injections thus cause 1.3 million deaths and almost 26 million years of life lost, mainly because of transmission of hepatitis B and C, and HIV<sup>21</sup>.

Especially disquieting is the paucity of information on the extent and determinants of unsafe care in low- and middleincome countries. With unregulated commercialization of care, weaker quality control and health resource limitations, healthcare users in low-income countries may well be even more exposed to the risk of unintended patient harm than patients in high-income countries. The World Alliance for Patient Safety<sup>22</sup>, among others, advocates making patients safer through systemic interventions and a change in organizational culture rather than through the denunciation of individual health-care practitioners or administrators<sup>23</sup>. countries where people often get poor value for money  $(Box 3.2)^{15}$ .

Technical and safety parameters are not the only determinants of the outcomes of health care. The disappointingly low success rate in preventing mother-to-child transmission (MTCT) of HIV in a study in the Côte d'Ivoire (Figure 3.2) illustrates that other features of the organization of health care are equally critical – good drugs are

## **Box 3.2** When supplier-induced and consumer-driven demand determine medical advice: ambulatory care in India

"Ms. S is a typical patient who lives in urban Delhi. There are over 70 private-sector medical care providers within a 15-minute walk from her house (and virtually any household in her city). She chooses the private clinic run by Dr. SM and his wife. Above the clinic a prominent sign says "Ms. MM, Gold Medalist, MBBS", suggesting that the clinic is staffed by a highly proficient doctor (an MBBS is the basic degree for a medical doctor as in the British 2 system). As it turns out, Ms. MM is rarely at the clinic. We were told that she sometimes comes at 4 a.m. to avoid the long lines that form if people know she is there. We later discover that she has "franchised" her name to a number of different clinics. Therefore, Ms. S sees Dr. SM and his wife, both of whom were trained in traditional Ayurvedic medicine through a six-month long-distance course. The doctor and his wife sit at a small table surrounded, on one side, by a large number of bottles full of pills, and on the other, a bench with patients on them, which extends into the street. Ms. S sits at the end of this bench. Dr. SM and his wife are the most popular medical care providers in the neighbourhood, with more than 200 patients every day. The doctor spends an average of 3.5 minutes with each patient, asks 3.2 questions, and performs an average of 2.5 examinations. Following the diagnosis, the doctor takes two or three different pills, crushes them using a mortar and pestle, and makes small paper packets from the resulting powder which he gives to Ms. S and asks her to take for two or three days. These medicines usually include one antibiotic and one analgesic and anti-inflammatory drug. Dr. SM tells us that he constantly faces unrealistic patient expectations, both because of the high volume of patients and their demands for treatments that even Dr. SM knows are inappropriate. Dr. SM and his wife seem highly motivated to provide care to their patients and even with a very crowded consultation room they spend more time with their patients than a public sector doctor would. However, they are not bound by their knowledge [...] and instead deliver health care like the crushed pills in a paper packet, which will result in more patients willing to pay more for their services"24.

not enough. How services deal with people is also vitally important. Surveys in Australia, Canada, Germany, New Zealand, the United Kingdom and the United States show that a high number of patients report safety risks, poor care coordination and deficiencies in care for chronic conditions<sup>25</sup>. Communication is often inadequate and lacking in information on treatment schedules. Nearly one in every two patients feels that doctors only rarely or never asked their opinion about treatment. Patients may consult different providers for related or even for the same conditions which, given the lack of coordination among these providers, results in duplication and contradictions<sup>25</sup>. This situation is similar to that reported in other countries, such as Ethiopia<sup>26</sup>, Pakistan<sup>27</sup> and Zimbabwe<sup>28</sup>.

There has, however, been progress in recent years. In high-income countries, confrontation with chronic disease, mental health problems, multi-morbidity and the social dimension of disease has focused attention on the need for more comprehensive and person-centred approaches and continuity of care. This resulted not only from client pressure, but also from professionals who realized the critical importance of such

## **Figure 3.2** Lost opportunities for prevention of mother-to-child transmission of HIV (MTCT) in Côte d'Ivoire<sup>29</sup>: only a tiny fraction of the expected transmissions are actually prevented



features of care in achieving better outcomes for their patients. Many health professionals have begun to appreciate the limitations of narrow clinical approaches, for example, to cardiovascular disease. As a result there has been a welcome blurring of the traditional boundaries between curative care, preventive medicine and health promotion.

In low-income countries, this evolution is also visible. In recent years, many of the programmes targeting infectious disease priorities have given careful consideration to comprehensiveness, continuity and patient-centredness. Maternal and child health services have often been at the forefront of these attempts, organizing a continuum of care and a comprehensive approach. This process has been consolidated through the joint UNICEF/WHO Integrated Management of Childhood Illness initiatives<sup>30</sup>. Their experience with programmes such as the WHO's Extended Programme for Immunization has put health professionals in many developing countries a step ahead compared to their high-income country colleagues, as they more readily see themselves responsible not just for patients, but also for population coverage. More recently, HIV/AIDS programmes have drawn the attention of providers and policy-makers to the importance of counselling, continuity of care, the complementarity of prevention, treatment and palliation and critically, to the value of empathy and listening to patients.

#### Understanding people: person-centred care

When people are sick they are a great deal less concerned about managerial considerations of productivity, health targets, cost-effectiveness and rational organization than about their own predicament. Each individual has his or her own way of experiencing and coping with health problems within their specific life circumstances<sup>31</sup>. Health workers have to be able to handle that diversity. For health workers at the interface between the population and the health services, the challenge is much more complicated than for a specialized referral service: managing a welldefined disease is a relatively straightforward technical challenge. Dealing with health problems, however, is complicated as people need to be understood holistically: their physical, emotional and social concerns, their past and their future, and the realities of the world in which they live. Failure to deal with the whole person in their specific familial and community contexts misses out on important aspects of health that do not immediately fit into disease categories. Partner violence against women (Box 3.3), for example, can be detected, prevented or mitigated by health services that are sufficiently close to the communities they serve and by health workers who know the people in their community.

People want to know that their health worker understands them, their suffering and the constraints they face. Unfortunately, many providers neglect this aspect of the therapeutic relation, particularly when they are dealing with disadvantaged groups. In many health services, responsiveness and person-centredness are treated as luxury goods to be handed out only to a selected few.

Over the last 30 years, a considerable body of research evidence has shown that personcentredness is not only important to relieve the patient's anxiety but also to improve the provider's job satisfaction<sup>50</sup>. The response to a health problem is more likely to be effective if the provider understands its various dimensions<sup>51</sup>. For a start, simply asking patients how they feel about their illness, how it affects their lives, rather than focusing only on the disease, results in measurably increased trust and compliance<sup>52</sup> that allows patient and provider to find a common ground on clinical management, and facilitates the integration of prevention and health promotion in the therapeutic response<sup>50,51</sup>. Thus, person-centredness becomes the "clinical method of participatory democracy"53, measurably improving the quality of care, the success of treatment and the quality of life of those benefiting from such care (Table 3.2).

In practice, clinicians rarely address their patients' concerns, beliefs and understanding of illness, and seldom share problem management options with them<sup>58</sup>. They limit themselves to simple technical prescriptions, ignoring the complex human dimensions that are critical to the appropriateness and effectiveness of the care they provide<sup>59</sup>.

#### Box 3.3 The health-care response to partner violence against women

Intimate partner violence has numerous well-documented consequences for women's health (and for the health of their children), including injuries, chronic pain syndromes, unintended and unwanted pregnancies, pregnancy complications, sexually transmitted infections and a wide range of mental health problems<sup>32,33,34,35,36,37</sup>. Women suffering from violence are frequent health-care users <sup>38,39</sup>.

Health workers are, therefore, well placed to identify and provide care to the victims of violence, including referral for psychosocial, legal and other support. Their interventions can reduce the impact of violence on a woman's health and well-being, and that of her children, and can also help prevent further violence.

Research has shown that most women think health-care providers should ask about violence<sup>40</sup>. While they do not expect them to solve their problem, they would like to be listened to and treated in a non-judgemental way and get the support they need to take control over their decisions. Health-care providers often find it difficult to ask women about violence. They lack the time and the training and skills to do it properly, and are reluctant to be involved in judicial proceedings.

The most effective approach for health providers to use when responding to violence is still a matter of debate<sup>41</sup>. They are generally advised to ask all women about intimate partner abuse as a routine part of any health assessment, usually referred to as "screening" or routine enquiry<sup>42</sup>. Several reviews found that this technique increased the rate of identification of women experiencing violence in antenatal and primary-care clinics, but there was little evidence that this was sustained<sup>40</sup>, or was effective in terms of health outcomes<sup>43</sup>. Among women who have stayed in shelters, there is evidence that those who received a specific counselling and advocacy service reported a lower rate of re-abuse and an improved quality of life<sup>44</sup>. Similarly, among women experiencing violence during pregnancy, those who received "empowerment counselling" reported improved functioning and less psychological and non-severe physical abuse, and had lower postnatal depression scores<sup>45</sup>.

While there is still no consensus on the most effective strategy, there is growing agreement that health services should aim to identify and support women experiencing violence<sup>46</sup>, and that health-care providers should be well educated about these issues, as they are essential in building capacity and skills. Health-care providers should, as a minimum, be informed about violence against women, its prevalence and impact on health, when to suspect it and how to best respond. Clearly, there are technical dimensions to this. For example, in the case of sexual assault, providers need to be able to provide the necessary treatment and care, including provision of emergency contraception and prophylaxis for sexually transmitted infections, including HIV where relevant, as well as psychosocial support. There are other dimensions too: health workers need to be able to document any injuries as completely and carefully as possible<sup>47,48,49</sup> and they need to know how to work with communities – in particular with men and boys – on changing attitudes and practices related to gender inequality and violence.

 Table 3.2 Person-centredness: evidence of its

 contribution to quality of care and better outcomes

Improved treatment intensity and quality of life – Ferrer  $(2005)^{54}$ 

Better understanding of the psychological aspects of a patient's problems – Gulbrandsen (1997)<sup>55</sup>

Improved satisfaction with communication – Jaturapatporn (2007)<sup>56</sup>

Improved patient confidence regarding sensitive problems – Kovess-Masféty (2007)<sup>57</sup>

Increased trust and treatment compliance – Fiscella (2004)<sup>52</sup>

Better integration of preventive and promotive care – Mead (1982)<sup>50</sup>

Thus, technical advice on lifestyle, treatment schedule or referral all too often neglects not only the constraints of the environment in which people live, but also their potential for selfhelp in dealing with a host of health problems ranging from diarrhoeal disease<sup>60</sup> to diabetes management<sup>61</sup>. Yet, neither the nurse in Niger's rural health centre nor the general practitioner in Belgium can, for example, refer a patient to hospital without negotiating<sup>62,63</sup>: along with medical criteria, they have to take into account the patient's values, the family's values, and their lifestyle and life perspective<sup>64</sup>.

Few health providers have been trained for person-centred care. Lack of proper preparation is compounded by cross-cultural conflicts, social stratification, discrimination and stigma<sup>63</sup>. As a consequence, the considerable potential of people to contribute to their own health through lifestyle, behaviour and self-care, and by adapting

#### Box 3.4 Empowering users to contribute to their own health

Families can be empowered to make choices that are relevant to their health. Birth and emergency  $plans^{66}$ , for example, are based on a joint examination between the expectant mother and health staff – well before the birth – of her expectations regarding childbirth. Issues discussed include where the birth will take place, and how support for care of the home and any other children will be organized while the woman is giving birth. The discussion can cover planning for expenses, arrangements for transport and medical supplies, as well as identification of a compatible blood donor in case of haemorrhage. Such birth plans are being implemented in countries as diverse as Egypt, Guatemala, Indonesia, the Netherlands and the United Republic of Tanzania. They constitute one example of how people can participate in decisions relating to their health in a way that empowers them<sup>67</sup>. Empowerment strategies can improve health and social outcomes through several pathways; the condition for success is that they are embedded in local contexts and based on a strong and direct relationship between people and their health workers<sup>68</sup>. The strategies can relate to a variety of areas, as shown below:

- developing household capacities to stay healthy, make healthy decisions and respond to emergencies France's self-help organization of diabetics<sup>69</sup>, South Africa's family empowerment and parent training programmes<sup>70</sup>, the United Republic of Tanzania's negotiated treatment plans for safe motherhood<sup>71</sup>, and Mexico's active ageing programme<sup>72</sup>;
- increasing citizens' awareness of their rights, needs and potential problems Chile's information on entitlements<sup>73</sup> and Thailand's Declaration of Patients' Rights<sup>74</sup>;
- strengthening linkages for social support within communities and with the health system support and advice to family caregivers dealing with dementia in developing country settings<sup>75</sup>, Bangladesh's rural credit programmes and their impact on care-seeking behaviour<sup>76</sup>, and Lebanon's neighbourhood environment initiatives<sup>77</sup>.

professional advice optimally to their life circumstances is underutilized. There are numerous, albeit often missed, opportunities to empower people to participate in decisions that affect their own health and that of their families (Box 3.4). They require health-care providers who can relate to people and assist them in making informed choices. The current payment systems and incentives in community health-care delivery often work against establishing this type of dialogue<sup>65</sup>. Conflicts of interest between provider and patient, particularly in unregulated commercial settings, are a major disincentive to personcentred care. Commercial providers may be more courteous and client-friendly than in the average health centre, but this is no substitute for personcentredness.

#### **Comprehensive and integrated responses**

The diversity of health needs and challenges that people face does not fit neatly into the discrete diagnostic categories of textbook promotive, preventive, curative or rehabilitative care<sup>78,79</sup>. They call for the mobilization of a comprehensive range of resources that may include health promotion and prevention interventions as well as diagnosis and treatment or referral, chronic or long-term home care, and, in some models, social services<sup>80</sup>. It is at the entry point of the system, where people first present their problem, that the need for a comprehensive and integrated offer of care is most critical.

Comprehensiveness makes managerial and operational sense and adds value (Table 3.3). People take up services more readily if they know a comprehensive spectrum of care is on offer. Moreover, it maximizes opportunities for preventive care and health promotion while reducing unnecessary reliance on specialized or hospital care<sup>81</sup>. Specialization has its comforts, but the fragmentation it induces is often visibly counterproductive and inefficient: it makes no sense to monitor the growth of children and neglect the health of their mothers (and vice versa), or to treat someone's tuberculosis without considering their HIV status or whether they smoke.

 Table 3.3 Comprehensiveness: evidence of its

 contribution to quality of care and better outcomes

Better health outcomes – Forrest  $(1996)^{82}$ , Chande  $(1996)^{83}$ , Starfield  $(1998)^{84}$ 

Increased uptake of disease-focused preventive care (e.g. blood pressure screen, mammograms, pap smears) – Bindman (1996)<sup>85</sup>

Fewer patients admitted for preventable complications of chronic conditions – Shea (1992)<sup>86</sup>

That does not mean that entry-point health workers should solve all the health problems that are presented there, nor that all health programmes always need to be delivered through a single integrated service-delivery point. Nevertheless, the primary-care team has to be able to respond to the bulk of health problems in the community. When it cannot do so, it has to be able to mobilize other resources, by referring or by calling for support from specialists, hospitals, specialized diagnostic and treatment centres, public-health programmes, long-term care services, home-care or social services, or self-help and other community organizations. This cannot mean giving up responsibility: the primary-care team remains responsible for helping people to navigate this complex environment.

Comprehensive and integrated care for the bulk of the assorted health problems in the community is more efficient than relying on separate services for selected problems, partly because it leads to a better knowledge of the population and builds greater trust. One activity reinforces the other. Health services that offer a comprehensive range of services increase the uptake and coverage of, for example, preventive programmes, such as cancer screening or vaccination (Figure 3.3). They prevent complications and improve health outcomes.

Comprehesive services also facilitate early detection and prevention of problems, even in the absence of explicit demand. There are individuals and groups who could benefit from care even if they express no explicit spontaneous demand, as in the case of women attending the health centres in Ouallam district, Niger, or people with undiagnosed high blood pressure or depression. Early detection of disease, preventive care to reduce the incidence of poor health, health promotion to reduce risky behaviour, and addressing social and other determinants of health all require the health service to take the initiative. For many problems, local health workers are the only ones who are in a position to effectively address problems in the community: they are the only ones, for example, in a position to assist parents with care in early childhood development, itself an important determinant of later health, well-being and productivity<sup>87</sup>. Such interventions require proactive health teams offering a comprehensive range of services. They depend on a close and trusting relationship between the health services and the communities they serve, and, thus, on health workers who know the people in their community<sup>88</sup>.

#### **Continuity of care**

Understanding people and the context in which they live is not only important in order to provide a comprehensive, person-centred response, it also conditions continuity of care. Providers often behave as if their responsibility starts when a patient walks in and ends when they leave the premises. Care should not, however, be limited to the moment a patient consults nor be confined to the four walls of the consultation room. Concern for outcomes mandates a consistent and coherent approach to the management of the patient's problem, until the problem is resolved or the risk that justified follow-up has disappeared. Continuity of care is an important determinant of effectiveness, whether for chronic disease management, reproductive health, mental health or for making sure children grow up healthily (Table 3.4).



 Visal r227 relative tenties, covering a population or rominion people.
 Vaccination coverage was not included in the assessment of overall health-centre performance across a range of services.

<sup>c</sup> Includes vaccination of children not belonging to target population.

**Table 3.4** Continuity of care: evidence of its

 contribution to quality of care and better outcomes

Lower all-cause mortality – Shi (2003)<sup>90</sup>, Franks (1998)<sup>97</sup>, Villalbi (1999)<sup>92</sup>, PAHO (2005)<sup>93</sup>

Better access to care – Weinick  $(2000)^{94}$ , Forrest  $(1998)^{95}$ 

Less re-hospitalization – Weinberger (1996)<sup>96</sup>

Fewer consultations with specialists – Woodward (2004)<sup>97</sup>

Less use of emergency services - Gill (2000)98

Better detection of adverse effects of medical interventions – Rothwell (2005)<sup>99</sup>, Kravitz (2004)<sup>100</sup>

Continuity of care depends on ensuring continuity of information as people get older, when they move from one residence to another, or when different professionals interact with one particular individual or household. Access to medical records and discharge summaries, electronic, conventional or client-held, improves the choice of the course of treatment and of coordination of care. In Canada, for example, one in seven people attending an emergency department had medical information missing that was very likely to result in patient harm<sup>101</sup>. Missing information is a common cause of delayed care and uptake of unnecessary services<sup>102</sup>. In the United States, it is associated with 15.6% of all reported errors in ambulatory care<sup>103</sup>. Today's information and communication technologies, albeit underutilized, gives unprecedented possibilities to improve the circulation of medical information at an affordable cost<sup>104</sup>, thus enhancing continuity, safety and learning (Box 3.5). Moreover, it is no longer the exclusive privilege of high-resource environments, as the Open Medical Record System demonstrates: electronic health records developed through communities of practice and open-source software are facilitating continuity and quality of care for patients with HIV/AIDS in many low-income countries<sup>105</sup>.

Better patient records are necessary but not sufficient. Health services need to make active efforts to minimize the numerous obstacles to continuity of care. Compared to payment by capitation or by fee-for-episode, out-of-pocket fee-for-service payment is a common deterrent, not only to access, but also to continuity of care<sup>107</sup>. In Singapore, for example, patients were formerly not allowed to use their health savings account (Medisave) for outpatient treatment, resulting in patient delays and lack of treatment compliance for the chronically ill. This had become so problematic that regulations were changed. Hospitals are now encouraged to transfer patients with diabetes, high blood pressure, lipid disorder and stroke to registered general practitioners, with Medisave accounts covering ambulatory care<sup>108</sup>.

Other barriers to continuity include treatment schedules requiring frequent clinic attendance that carry a heavy cost in time, travel expenses or lost wages. They may be ill-understood and patient motivation may be lacking. Patients may get lost in the complicated institutional environment of referral hospitals or social services. Such problems need to be anticipated and recognized at an early stage. The effort required from health workers is not negligible: negotiating the modalities of the treatment schedule with the patients so as to maximize the chances that it can be completed; keeping registries of clients with chronic conditions; and creating communication channels through home visits, liaison with community workers, telephonic reminders and text messages to re-establish interrupted continuity. These mundane tasks often make the difference between a successful outcome and a treatment failure, but are rarely rewarded. They are much easier to implement when patient and caregiver have clearly identified how and by whom followup will be organized.

#### A regular and trusted provider as entry point

Comprehensiveness, continuity and person-centredness are critical to better health outcomes. They all depend on a stable, long-term, personal relationship (a feature also called "longitudinality"<sup>84</sup>) between the population and the professionals who are their entry point to the health system.

Most ambulatory care in conventional settings is not organized to build such relationships. The busy, anonymous and technical environment of hospital outpatient departments, with their many specialists and sub-specialists, produce mechanical interactions between nameless individuals and an institution – not people-centred care. Smaller clinics are less anonymous, but the care they provide is often more akin to a commercial or administrative transaction that starts and ends with the consultation than to a responsive problem-solving exercise. In this regard, private clinics do not perform differently than public health centres<sup>64</sup>. In the rural areas of low-income countries, governmental health centres are usually designed to work in close relationship with the community they serve. The reality is often different. Earmarking of resources and staff for selected programmes is increasingly leading to fragmentation<sup>109</sup>, while the lack of funds, the pauperization of the health staff and rampant commercialization makes building such relationships difficult<sup>110</sup>. There are many examples to the contrary, but the relationship between providers and their clients, particularly the poorer ones, is often not conducive to building relationships of understanding, empathy and trust<sup>62</sup>.

Building enduring relationships requires time. Studies indicate that it takes two to five years before its full potential is achieved<sup>84</sup> but, as the Alaska health centre mentioned at the beginning of this chapter shows, it drastically changes the way care is being provided. Access to the same team of health-care providers over time fosters the development of a relationship of trust between the individual and their health-care provider<sup>97,111,112</sup>. Health professionals are more likely to respect and understand patients they know

## **Box 3.5** Using information and communication technologies to improve access, quality and efficiency in primary care

Information and communication technologies enable people in remote and underserved areas to have access to services and expertise otherwise unavailable to them, especially in countries with uneven distribution or chronic shortages of physicians, nurses and health technicians or where access to facilities and expert advice requires travel over long distances. In such contexts, the goal of improved access to health care has stimulated the adoption of technology for remote diagnosis, monitoring and consultation. Experience in Chile of immediate transmission of electrocardiograms in cases of suspected myocardial infarction is a noteworthy example: examination is carried out in an ambulatory setting and the data are sent to a national centre where specialists confirm the diagnosis via fax or e-mail. This technology-facilitated consultation with experts allows rapid response and appropriate treatment where previously it was unavailable. The Internet is a key factor in its success, as is the telephone connectivity that has been made available to all health facilities in the country.

A further benefit of using information and communication technologies in primary-care services is the improved quality of care. Healthcare providers are not only striving to deliver more effective care, they are also striving to deliver safer care. Tools, such as electronic health records, computerized prescribing systems and clinical decision aids, support practitioners in providing safer care in a range of settings. For example, in a village in western Kenya, electronic health records integrated with laboratory, drug procurement and reporting systems have drastically reduced clerical labour and errors, and have improved follow-up care.

As the costs of delivering health care continue to rise, information and communication technologies provide new avenues for personalized, citizen-centred and home-centred care. Towards this end, there has been significant investment in research and development of consumer-friendly applications. In Cape Town, South Africa, an "on cue compliance service" takes the names and mobile telephone numbers of patients with tuberculosis (supplied by a clinic) and enters them into a database. Every half an hour, the on cue server reads the database and sends personalized SMS messages to the patients, reminding them to take their medication. The technology is low-cost and robust. Cure and completion rates are similar to those of patients receiving clinic-based DOTS, but at lower cost to both clinic and patient, and in a way that interferes much less with everyday life than the visits to the clinic<sup>106</sup>. In the same concept of supporting lifestyles linked to primary care, network devices have become a key element of an innovative community programme in the Netherlands, where monitoring and communication devices are built into smart apartments for senior citizens. This system reduces clinic visits and facilitates living independently with chronic diseases that require frequent checks and adjustment of medications.

Many clinicians who want to promote health and prevent illness are placing high hopes in the Internet as the place to go for health advice to complement or replace the need to seek the advice of a health professional. New applications, services and access to information have permanently altered the relationships between consumers and health professionals, putting knowledge directly into people's own hands.

**Table 3.5** Regular entry point: evidence of its

 contribution to quality of care and better outcomes

Increased satisfaction with services – Weiss (1996)<sup>116</sup>, Rosenblatt (1998)<sup>117</sup>, Freeman (1997)<sup>124</sup>, Miller (2000)<sup>125</sup>

Better compliance and lower hospitalization rate – Weiss (1996)<sup>116</sup>, Rosenblatt (1998)<sup>117</sup>, Freeman (1997)<sup>124</sup>, Mainous (1998)<sup>126</sup>

Less use of specialists and emergency services – Starfield (1998)<sup>82</sup>, Parchman (1994)<sup>127</sup>, Hurley (1989)<sup>128</sup>, Martin (1989)<sup>129</sup>, Gadomski (1998)<sup>130</sup>

Fewer consultations with specialists – Hurley (1989)<sup>128</sup>, Martin (1989)<sup>129</sup>

More efficient use of resources – Forrest (1996)<sup>82</sup>, Forrest (1998)<sup>95</sup>, Hjortdahl (1991)<sup>131</sup>, Roos (1998)<sup>132</sup>

Better understanding of the psychological aspects of a patient's problem – Gulbrandsen (1997)<sup>55</sup>

Better uptake of preventive care by adolescents – Ryan (2001)<sup>133</sup>

Protection against over-treatment - Schoen (2007)<sup>134</sup>

well, which creates more positive interaction and better communication<sup>113</sup>. They can more readily understand and anticipate obstacles to continuity of care, follow up on the progress and assess how the experience of illness or disability is affecting the individual's daily life. More mindful of the circumstances in which people live, they can tailor care to the specific needs of the person and recognize health problems at earlier stages.

This is not merely a question of building trust and patient satisfaction, however important these may be<sup>114,115</sup>. It is worthwhile because it leads to better quality and better outcomes (Table 3.5). People who use the same source of care for most of their health-care needs tend to comply better with advice given, rely less on emergency services, require less hospitalization and are more satisfied with care<sup>98</sup><sup>116,117,118</sup>. Providers save consultation time, reduce the use of laboratory tests and costs<sup>95,119,120</sup>, and increase uptake of preventive care<sup>121</sup>. Motivation improves through the social recognition built up by such relationships. Still, even dedicated health professionals will not seize all these opportunities spontaneously<sup>122,123</sup>. The interface between the population and their health services needs to be designed in a way that not only makes this possible, but also the most likely course of action.

#### **Organizing primary-care networks**

A health service that provides entry point ambulatory care for health- and health-related problems should, thus, offer a comprehensive range of integrated diagnostic, curative, rehabilitative and palliative services. In contrast to most conventional health-care delivery models, the offer of services should include prevention and promotion as well as efforts to tackle determinants of ill-health locally. A direct and enduring relationship between the provider and the people in the community served is essential to be able to take into account the personal and social context of patients and their families, ensuring continuity of care over time as well as across services.

In order for conventional health services to be transformed into primary care, i.e. to ensure that these distinctive features get due prominence, they must reorganized. A precondition is to ensure that they become directly and permanently accessible, without undue reliance on out-of-pocket payments and with social protection offered by universal coverage schemes. But another set of arrangements is critical for the transformation of conventional care – ambulatory- and institution-based, generalist and specialist – into local networks of primary-care centres<sup>135,136,137,138,139,140</sup>:

- bringing care closer to people, in settings in close proximity and direct relationship with the community, relocating the entry point to the health system from hospitals and specialists to close-to-client generalist primary-care centres;
- giving primary-care providers the responsibility for the health of a defined population, in its entirety: the sick and the healthy, those who choose to consult the services and those who choose not to do so;
- strengthening primary-care providers' role as coordinators of the inputs of other levels of care by giving them administrative authority and purchasing power.

#### Bringing care closer to the people

A first step is to relocate the entry point to the health system from specialized clinics, hospital outpatient departments and emergency services, to generalist ambulatory care in close-to-client settings. Evidence has been accumulating that this transfer carries measurable benefits in terms of relief from suffering, prevention of illness and death, and improved health equity. These findings hold true in both national and cross-national studies, even if all of the distinguishing features of primary care are not fully realized<sup>31</sup>.

Generalist ambulatory care is more likely or as likely to identify common life-threatening conditions as specialist care<sup>141,142</sup>. Generalists adhere to clinical practice guidelines to the same extent as specialists<sup>143</sup>, although they are slower to adopt them<sup>144,145</sup>. They prescribe fewer invasive interventions<sup>146,147,148,149</sup>, fewer and shorter hospitalizations<sup>127,133,149</sup> and have a greater focus on preventive care<sup>133,150</sup>. This results in lower overall health-care costs<sup>82</sup> for similar health outcomes<sup>146,151,152,153,154,155</sup> and greater patient satisfaction<sup>125,150,156</sup>. Evidence from comparisons between high-income countries shows that higher proportions of generalist professionals working in ambulatory settings are associated with lower overall costs and higher quality rankings<sup>157</sup>. Conversely, countries that increase reliance on specialists have stagnating or declining health outcomes when measured at the population

### Figure 3.4 Inappropriate investigations prescribed for simulated patients presenting with a minor stomach complaint, Thailand<sup>a,b, 162</sup>

Patients for whom inappropriate investigations were prescribed (%)



<sup>a</sup> Observation made in 2000, before introduction of Thailand's universal coverage scheme.
 <sup>b</sup> Cost to the patient, including doctor's fees, drugs, laboratory and technical investigations.

level, while fragmentation of care exacerbates user dissatisfaction and contributes to a growing divide between health and social services<sup>157,158,159</sup>. Information on low- and middle-income countries is harder to obtain<sup>160</sup>, but there are indications that patterns are similar. Some studies estimate that in Latin America and the Caribbean more reliance on generalist care could avoid one out of two hospital admissions<sup>161</sup>. In Thailand, generalist ambulatory care outside a hospital context has been shown to be more patient-centred and responsive as well as cheaper and less inclined to over-medicalization<sup>162</sup> (Figure 3.4).

The relocation of the entry point into the system from specialist hospital to generalist ambulatory care creates the conditions for more comprehensiveness, continuity and person-centredness. This amplifies the benefits of the relocation. It is particularly the case when services are organized as a dense network of small, close-to-client service delivery points. This makes it easier to have teams that are small enough to know their communities and be known by them, and stable enough to establish an enduring relationship. These teams require relational and organizational capacities as much as the technical competencies to solve the bulk of health problems locally.

### Responsibility for a well-identified population

In conventional ambulatory care, the provider assumes responsibility for the person attending the consultation for the duration of the consultation and, in the best of circumstances, that responsibility extends to ensuring continuity of care. This passive, response-to-demand approach fails to help a considerable number of people who could benefit from care. There are people who, for various reasons, are, or feel, excluded from access to services and do not take up care even when they are in need. There are people who suffer illness but delay seeking care. Others present risk factors and could benefit from screening or prevention programmes (e.g. for cervical cancer or for childhood obesity), but are left out because they do not consult: preventive services that are limited to service users often leave out those most in need<sup>163</sup>. A passive, response-to-demand

approach has a second untoward consequence: it lacks the ambition to deal with local determinants of ill-health – whether social, environmental or work-related. All this represents lost opportunities for generating health: providers that only assume responsibility for their customers concentrate on repairing rather than on maintaining and promoting health.

The alternative is to entrust each primary-care team with the explicit responsibility for a welldefined community or population. They can then be held accountable, through administrative measures or contractual arrangements, for providing comprehensive, continuous and person-centred care to that population, and for mobilizing a comprehensive range of support services - from promotive through to palliative. The simplest way of assigning responsibility is to identify the community served on the basis of geographical criteria - the classic approach in rural areas. The simplicity of geographical assignment, however, is deceptive. It follows an administrative, public sector logic that often has problems adapting to the emergence of a multitude of other providers. Furthermore, administrative geography may not coincide with sociological reality, especially in urban areas. People move around and may work in a different area than where they live, making the health unit closest to home actually an inconvenient source of care. More importantly, people value choice and may resent an administrative assignment to a particular health unit. Some countries find geographical criteria of proximity the most appropriate to define who fits in the population of responsibility, others rely on active registration or patient lists. The important point is not how but whether the population is well identified and mechanisms exist to ensure that nobody is left out.

Once such explicit comprehensive responsibilities for the health of a well-identified and defined population are assigned, with the related financial and administrative accountability mechanisms, the rules change.

The primary-care team has to broaden the portfolio of care it offers, developing activities and programmes that can improve outcomes, but which they might otherwise neglect<sup>164</sup>. This sets the stage for investment in prevention and

promotion activities, and for venturing into areas that are often overlooked, such as health in schools and in the workplace. It forces the primary-care team to reach out to and work with organizations and individuals within the community: volunteers and community health workers who act as the liaison with patients or animate grassroots community groups, social workers, self-help groups, etc.

- It forces the team to move out of the four walls of their consultation room and reach out to the people in the community. This can bring significant health benefits. For example, largescale programmes, based on home-visits and community animation, have been shown to be effective in reducing risk factors for neonatal mortality and actual mortality rates. In the United States, such programmes have reduced neonatal mortality by 60% in some settings<sup>165</sup>. Part of the benefit is due to better uptake of effective care by people who would otherwise remain deprived. In Nepal, for example, the community dynamics of women's groups led to the better uptake of care, with neonatal and maternal mortality lower than in control communities by 29% and 80%, respectively<sup>166</sup>.
- It forces the team to take targeted initiatives, in collaboration with other sectors, to reach the excluded and the unreached and tackle broader determinants of ill-health. As Chapter 2 has shown, this is a necessary complement to establishing universal coverage and one where local health services play a vital role. The 2003 heatwave in western Europe, for example, highlighted the importance of reaching out to the isolated elderly and the dramatic consequences of failing to do so: an excess mortality of more than 50 000 people<sup>167</sup>.

For people and communities, formal links with an identifiable source of care enhance the likelihood that long-term relationships will develop; that services are encouraged to pay more attention to the defining features of primary care; and that lines of communication are more intelligible. At the same time, coordination linkages can be formalized with other levels of care – specialists, hospitals or other technical services – and with social services.

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#### The primary-care team as a hub of coordination

Primary-care teams cannot ensure comprehensive responsibility for their population without support from specialized services, organizations and institutions that are based outside the community served. In resource-constrained circumstances, these sources of support will typically be concentrated in a "first referral level district hospital". Indeed, the classic image of a healthcare system based on PHC is that of a pyramid with the district hospital at the top and a set of (public) health centres that refer to the higher authority.

In conventional settings, ambulatory care professionals have little say in how hospitals and specialized services contribute – or fail to contribute – to the health of their patients, and feel little inclination to reach out to other institutions and stakeholders that are relevant to the health of the local community. This changes if they are entrusted with responsibility for a defined population and are recognized as the regular point of entry for that population. As health-care networks expand, the health-care landscape becomes far more crowded and pluralistic. More resources allow for diversification: the range of specialized services that comes within reach may include emergency services, specialists, diagnostic infrastructure, dialysis centres, cancer screening, environmental technicians, long-term care institutions, pharmacies, etc. This represents new opportunities, provided the primary-care teams can assist their community in making the best use of that potential, which is particularly critical to public health, mental health and longterm care<sup>168</sup>.

The coordination (or gatekeeping) role this entails effectively transforms the primary-care pyramid into a network, where the relations between the primary-care team and the other institutions and services are no longer based only on top-down hierarchy and bottom-up referral, but on cooperation and coordination (Figure 3.5). The primary-care team then becomes the mediator between the community and the other levels





of the health system, helping people navigate the maze of health services and mobilizing the support of other facilities by referring patients or calling on the support of specialized services.

This coordination and mediation role also extends to collaboration with other types of organizations, often nongovernmental. These can provide significant support to local primary care. They can help ensure that people know what they are entitled to and have the information to avoid substandard providers<sup>169,170</sup>. Independent ombudsman structures or consumer organizations can help users handle complaints. Most importantly, there is a wealth of self-help and mutual support associations for diabetics, people living with handicaps and chronic diseases that can help people to help themselves<sup>171</sup>. In the United States alone, more than five million people belong to mutual help groups while, in recent years, civil society organizations dealing with health and health-related issues, from self-help to patient's rights, have been mushrooming in many low- and middle-income countries. These groups do much more than just inform patients. They help people take charge of their own situation, improve their health, cope better with illhealth, increase self-confidence and diminish over-medicalization<sup>172</sup>. Primary-care teams can only be strengthened by reinforcing their linkages with such groups.

Where primary-care teams are in a position to take on this coordinator role, their work becomes more rewarding and attractive, while the overall effects on health are positive. Reliance on specialists and hospitalization is reduced by filtering out unnecessary uptake, whereas patient delay is reduced for those who do need referral care, the duration of their hospitalization is shortened, and post-hospitalization follow-up is improved<sup>83,128,129</sup>.

The coordination function provides the institutional framework for mobilizing across sectors to secure the health of local communities. It is not an optional extra but an essential part of the remit of primary-care teams. This has policy implications: coordination will remain wishful thinking unless the primary-care team has some form of either administrative or financial leverage. Coordination also depends on the different institutions' recognition of the key role of the primary-care teams. Current professional education systems, career structure and remuneration mechanisms most often give signals to the contrary. Reversing these well-entrenched disincentives to primary care requires strong leadership.

#### Monitoring progress

The switch from conventional to primary care is a complex process that cannot be captured in a single, universal metric. Only in recent years has it been possible to start disentangling the effects of the various features that define primary care. In part, this is because the identification of the features that make the difference between primary care and conventional health-care delivery has taken years of trial and error, and the instruments to measure them have not been generalized. This is because these features are never all put into place as a single package of reforms, but are the result of a gradual shaping and transformation of the health system. Yet, for all this complexity, it is possible to measure progress, as a complement to the follow-up required for measuring progress towards universal coverage.

The first dimension to consider is the extent to which the organizational measures required to switch to primary care are being put into place.

- Is the predominant type of first-contact provider being shifted from specialists and hospitals to generalist primary-care teams in close proximity to where the people live?
- Are primary-care providers being made responsible for the health of all the members of a well-identified population: those who attend health services and those who do not?
- Are primary-care providers being empowered to coordinate the various inputs of specialized, hospital and social services, by strengthening their administrative authority and purchasing power?

The second dimension to consider is the extent to which the distinctive features of primary care are gaining prominence.

Person-centredness: is there evidence of improvement, as shown by direct observation and user surveys?



- Comprehensiveness: is the portfolio of primary-care services expanding and becoming more comprehensive, reaching the full essential benefits package, from promotion through to palliation, for all age groups?
- Continuity: is information for individuals being recorded over the life-course, and transferred between levels of care in cases of referral and to a primary-care unit elsewhere when people relocate?
- Regular entry point: are measures taken to ensure that providers know their clients and vice versa?

This should provide the guidance to policy-makers as to the progress they are making with the transformation of health-care delivery. However, they do not immediately make it possible to attribute health and social outcomes to specific aspects of the reform efforts. In order to do so, the monitoring of the reform effort needs to be complemented with a much more vigorous research agenda. It is revealing that the Cochrane Review on strategies for integrating primary-health services in lowand middle-income countries could identify only one valid study that took the user's perspective into account<sup>160</sup>. There has been a welcome surge of research on primary care in high-income countries and, more recently, in the middle-income countries that have launched major PHC reforms. Nevertheless, it is remarkable that an industry that currently mobilizes 8.6% of the world's GDP invests so little in research on two of its most effective and cost-effective strategies: primary care and the public policies that underpin and complement it.

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