King's Fund

Patient and public involvement in Primary Care Groups and Trusts

Dagenham case study

July 2001

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Acknowledgements

Undertaking six concurrent case studies across London has been challenging. Happily, in every locality I have met people with enthusiasm, interest and good humour. Thank you to everyone for supporting the research, giving up your time to talk to me and welcoming me as a participant and observer in your many events and activities.

In particular, I would like to thank Catherine Burns, Doreen Stevens, Sidney Ramel, Dr Ghosh, Sharon Paradine and all the members of the Dagenham public involvement subgroup.

Will Anderson, July 2001

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Introduction

This report has been written for the members and officers of Barking and Dagenham Primary Care Trust (formerly Dagenham Primary Care Group) and their partners in the local health economy. It presents the results of a study of Dagenham PCG's patient and public involvement (PPI) work between February 2000 and April 2001.

Dagenham was one of six case studies participating in a King's Fund study of PPI in primary care groups and trusts, funded by the Health in Partnership initiative of the Department of Health. This report is one of six case study reports from each of the six sites. The sites were:

- Central Croydon PCG
- City & Hackney PCG (became City & Hackney PCT in April 2001)
- Dagenham PCG (became part of Barking & Dagenham PCT in April 2001)
- Harrow East & Kingsbury PCG
- Hayes & Harlington Directorate, Hillingdon PCT (formerly Hayes and Harlington PCG)
- North Lewisham PCG

All but one of these case study reports are presented in the same way in order to enable comparison between them. This report is divided into two main sections: a descriptive overview and a more detailed analysis. Although the headings used are not ideal for every case study, and may not always seem intuitive, they provide a guiding framework both for comparison of the individual case reports and for the development of the final output from the study.

A full 'cross-case analysis' will be published early in 2002, designed as an accessible guide for practitioners rather than as a pure research report.

Description

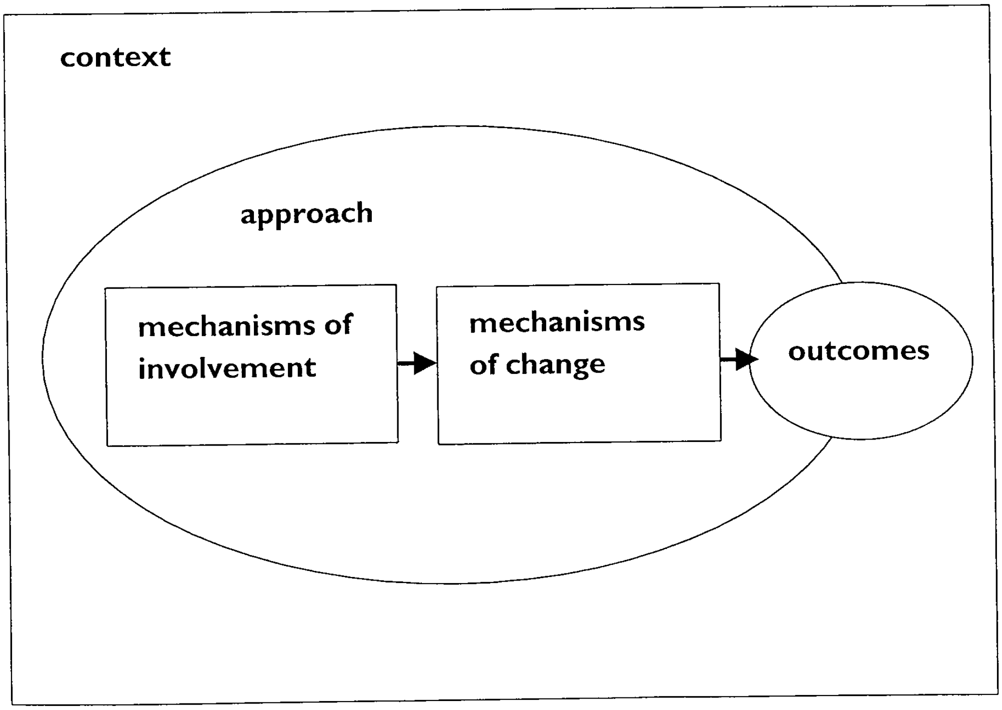
The model

This section describes both the detail of the PPI work that was undertaken and the broader context which shaped this work, including local history, organisational priorities and professional values.

The model, based on that of Pawson and Tilley (*Realistic Evaluation*, Sage, 1997), has five different elements: context, approach, mechanisms of involvement, mechanisms of change and outcomes. Together, these offer a comparative description of each locality. In summary:

- The context is the givens: the things you do not have much choice about.
- The approach is the choices that have been made (recently or otherwise) to shape the form of local PPI.
- The mechanisms of involvement are the specific PPI initiatives undertaken.
- The mechanisms of change are the processes by which PPI has an impact.
- Outcomes are the results (which may include changes in processes).

The main point of the model is this: if something works in one place, it may not work in another. To get PPI right, you have to make it work for your circumstances and your values. Similarly, in order to make sense of PPI initiatives, we have to attend to local history and local priorities as well as to the detail of how they are actually implemented.



Context

- Dagenham PCG was established in April 1999. It merged with Barking PCG in April 2001 to become the Barking and Dagenham PCT (coterminus with the local authority). Dagenham is an unusually homogenous part of London: a white, working class community with considerable local unemployment and related deprivation. However the principal primary care providers, the GPs, are almost all of South Asian ethnic origin; most are single-handers and many are approaching retirement. The PCG covered a population of 86000.
- The PCG board struggled to establish common values and an inclusive manner of working, not helped by early executive problems which culminated in the suspension of the first chief officer. The unwillingness of many of the GPs to accept the skills and values which the non-medical members brought to the board lead to considerable frustration among the latter group and the loss of the social services representative. PPI has not been a shared commitment of board members.
- The lay member sees her role as representing the interests of local people on the board, drawing on her wealth of experience in the local community and voluntary sector. However this experience has not been valued by all the board members, nor has her individual voice as a lay person always been respected.
- There is little local history of public involvement in health care for the PCG to build on. There are two PPGs in the area, one of which (the Gables PPG) has shaped a clear role for itself beyond fund-raising – it was fortunate to be working with the one GP in the area who has a very clear commitment to PPI.
- The PCG has a public involvement subgroup whose members include the Commissioning & Development (C&D) manager, the lay member, one of the nurse members, the health authority non-exec and the chair and GO from the Porters Avenue PPG. The King's Fund researcher also played an active part in this group. It met monthly to plan public involvement work.
- There is considerable experience and understanding of PPI among the members of the subgroup, but these skills have not been fully exploited because of the lack of organisational commitment and leadership. Although there is no tradition of partnership-working in primary care, contacts beyond the PCG (particularly in the voluntary sector) have been useful in the development of particular PPI initiatives.
- The C&D manager has provided the main officer support to the group, but this has been limited by her other commitments in a small team undergoing rapid development. There has been no budget for PPI but small amounts of funding have been made available for projects identified by the subgroup.

Approach

- Members of the public involvement subgroup have not been short of enthusiasm and ideas. However, turning these ideas into practice has proved a struggle, mainly because of the mismatch between the extent of the group's ambitions and the lack of organisational commitment and capacity to support PPI.
- The approach of the subgroup was dominated by a desire to improve the quality of local primary care services and to integrate primary care into a wider community-based process of promoting health.
- The subgroup's approach was both practical and idealistic. It was about making simple changes to improve current practice, such as providing better information about local services, as well as changing the culture of professional practice and relationships.
- A dominant theme of the subgroup's discussions was the development of patient participation at practice level. This reflects both the local history of the Gables PPG and the commitment to improving the quality of frontline services. PPGs were seen as vehicles for patient education (about both health issues and use

of services), for enhancing clinician-patient relationships, and for slowly changing how services are delivered.

- The other main concern of the subgroup was to hear the voices of local people who do not usually have any voice in decision-making about health, reflecting the community-focussed values of the subgroup members, particularly the lay member. This was realised in a specific research project, *Hearing the Voices of Vulnerable People in Dagenham.*
- The subgroup also picked up on local opportunities for PPI where they arise, such as participating in health fairs run by the local Age Concern.
- The lack of PCG corporate interest in PPI isolated activity to the subgroup. This meant that there was little attention paid to how the organisation could systematically embrace lay voices – the lay member herself had to struggle to sustain a meaningful role on the board.
- No strategy for PPI has been produced. This reflects the problems with organisational commitment and capacity, but also the open-ended, changeable and opportunistic character of the subgroup's discussions.

Mechanisms of involvement and mechanisms of change

- Lay member. The lay member's role was limited by the dominant professional priorities of many of the other board members. However, this made her voice all the more important in beginning a process of shifting the values of the organisation.
- Board meetings. These were run with little regard for public attendees. Initially, members of the public were kept completely to the margins until the board was challenged and forced to open one side of the table to members of the public.
- PPG development. All practices were encouraged to develop PPGs. The chair of Gables PPG and the lay member offered personal support to GPs with an interest in developing patient participation.
- *Preparing Professionals for Partnership with the Public.* This London region initiative was identified by the subgroup as a means for providing the necessary professional development to support patient participation with practices. Implementation of the programme has just begun.
- The subgroup. Although the public involvement subgroup was principally a planning group of the PCG, it was used by the chair of the Gables PPG as a route to raise practice issues with officers of the PCG.
- *Hearing the Voices of Vulnerable People in Dagenham.* This research project was designed as a means of hearing the voices of people with a high dependence on health services but who were unable to express their views and feelings about their needs and services. A free-lance researcher was contracted to undertake interviews with local patients and carers, recruited through voluntary organisations. The report was presented to a public meeting during Carers' Week in June 2001.
- Age Concern educational outreach. The PCG participated in special Age Concern health fair s with older people's groups, providing health and service information.
- Because of the resistance to PPI at board level, the mechanisms of change for the PCG were weak.

Outcomes achieved

- A tradition of thinking about patient and community interests (for the new PCT to draw on)
- Some moderation of professional values and priorities by alternative perspectives
- Corporate commitment to the development of better professional-patient relationships
- Completion of a significant piece of research into patient/carer views
- Improved links with the local community/voluntary sector

Analysis

Structure

The structure of the analysis reflects the structure of the main output of the study – a practitioners' guide to PPI in primary care. Although this structure suits some of the case studies better than others, it has been consistently used for all of them in order to ensure that the guide is strongly rooted in the results of the research.

The structure aims to be an accessible framework which covers all the key issues which people involved in PPI work are likely to be concerned about – as well as providing plenty of hooks on which the research themes from the study can be hung.

The gist of the structure of the guide is this:

Why bother?

The case for PPI always has to be made. If people pursue PPI only because it has to be done, not because they see any value in it, little is achieved and lots of people get annoyed. This chapter will encourage a critical attitude to all PPI work.

What counts as public involvement?

PPI means different things to different people. This chapter will map out the scope of what PPI can encompass, stressing the value of a broad and plural vision.

What do you want to achieve?

This chapter will look specifically at the aims which people identify for PPI, and the outcomes which actually emerge in practice. It will stress the importance of being open to unexpected outcomes and to changing your ideas of what success might mean as methods get put into practice.

Working out an approach

This chapter explores the many choices which people make, explicitly or implicitly, in developing PPI work, and the constraints upon these choices.

Making a difference

The question of making an impact (mechanisms of change) gets a chapter to itself, principally because it is so widely neglected.

Getting the details right

The detail of doing PPI is widely discussed in existing 'toolboxes'. This chapter will not repeat these, but draw attention to the detail of what has helped and hindered initiatives in the study.

Dangers and obstacles

This will be a critical discussion of how all the above can go wrong or be obstructed. The emphasis of the chapter will be on seizing the opportunities of PPI and not being put off by the range of common but narrowly conceived criticisms.

Doing it better

The final chapter will explore how people can learn from their experience of PPI, stressing the value of all types of evaluation and learning, however informal.

Why bother?

This was a very real question within the PCG because many of the board members had minimal interest in the involvement of lay voices in the business of primary care. The lay member found it difficult to gain the trust and acceptance of some of the GP members, who appeared to want to run the PCG with the same small business ethos as they ran their practices. Although she found support from the nurse, services and health authority members, this small group struggled to shift the culture of the board away from immediate business interests to the interests of patients and the local community.

The individuals who did support and engage in the PCG's PPI work in this adverse context were necessarily committed; no-one was pursuing PPI simply because they felt they had to. In response to the individualistic culture of general practice which dominated the PCG, they sought to define a vision of primary care based on productive relationships within a community context.

The members of the public involvement subgroup were clear that the needs of the local community could not be addressed effectively without active engagement and willingness to listen on the part of the PCG and primary care professionals. The perceived combination of a needy local community with the parlous state of local primary care services was the motivation for their commitment to changing the culture of local primary care.

What counts as public involvement?

As there was little commitment to, or interest in, PPI at board level, it was left to the small group of enthusiasts within the public involvement subgroup to define the scope of PPI. The members brought different interests to the group's discussions, but these discussions were open-ended and in no way constrained by a particular interpretation of what did and did not count as public involvement.

The group was very focussed on outcomes. What brought them together was a commitment to improving local primary care services (in particular) through any form of engagement with patients or local people. This meant that in the course of one discussion they were happy to discuss information provision, education campaigns, listening to marginalised voices, institutional communication, health promotion, doctor-patient relationships and promoting community solidarity. There was no sense that some of these activities might be more appropriate than others for their own attention or for the PCG's action. They were all needed.

The group also had a broad view of the kinds of methods which they might want to pursue. Their interest in enhancing the patient experience at practice level encompassed the development of PPGs, educational initiatives and GP training. However, they were also concerned to promote corporate-level action, particularly through partnership with the voluntary sector, which was perceived as an obvious and neglected route to involvement work.

What do you want to achieve?

The public involvement subgroup meetings were usually fairly unstructured events: although there was always an agenda, members of the group were more interested in opening up the discussion and giving voice to their own frustrations and concerns than always maintaining a focus on the group's business. Although this created problems, particularly in defining and following through plans of action, it did mean that everyone had a chance to express their own values and interests and see how much these cohered with those of other members. Consequently, the group did achieve a shared understanding about what they were seeking to achieve.

The heart of this understanding was a desire to improve the quality of local primary care services and the experience of primary (and community) care users. The group's core members had quite distinct but complementary perspectives on this goal. The lay member had an extensive knowledge of the needs of local people as the Director of the local carers' association and as a long-time resident; she knew how critical primary care was to vulnerable people, how much work needed to be done in transforming it and how much potential there was for partnership across the health economy. The chair of the PPG and the GP whose practice it was based in brought their related experiences of changing the professional-patient relationship and building a sense of community around the practice. The officers brought a day-to-day operational concern with improving primary care in a location where this presented particular challenges. The nurse member brought a professional understanding of the power relationships which dominated GP practice and the difficulties of changing these. These different perspectives were usually complementary and their interaction was productive, although time-consuming.

An important ingredient of this shared sense of purpose was the value placed on community. Again, this was expressed in different ways. The PPG chair described the aims of the PPG not only as improving services and relationships but also fostering a sense of community. The lay member wanted GP practices to be part of the community, not isolated businesses, in order that they could be open to local voices and contribute to a wider process of addressing community needs (which the voluntary sector was a critical part of). Thus there was a sense in the group that they were trying to do something bigger than improve services. They were pursuing a culture shift in primary care, from being a particular kind of service provider for individuals in need to being part of a shared community-based process of promoting health.

This community focus was also reflected in the group's concern that everyone in the local community should have a voice, which inspired the major research project into the voices of vulnerable people in Dagenham. This was not just about primary care but about the whole range of ways in which local people experienced services and struggled to meet their needs. The explicit aim of the project was to enable people who did not usually have a voice in health care decision-making to be heard; however it reflected the group's broader concern to enhance the understanding of primary care professionals of community needs and community resources.

The group's motivation may have come from a shared sense of the need to transform the nature and relationships of primary care, but their starting point was also their biggest obstacle. They set their sights on goals which they knew could only be achieved in the long term and then struggled to develop or sustain any process for pursuing these goals. In the event, the transformation of general practice was sidelined by opportunities with more immediate outcomes, such as the health fairs with Age Concern. Nonetheless, the decision to take part in *Preparing Professionals for Partnership with the Public* and the consistently high profile of the work of the Gables PPG kept the core interest alive.

Working out an approach

A number of contextual factors were crucial in defining the general approach which the PCG subgroup took to PPI.

First, the basic lack of corporate support for PPI ensured that the work was always marginal to the activity of the organisation. Although much of the PPI work reflected a priority for the PCG – primary care development – there were never any strong links between the organisation's on-going interests and the activity of the subgroup. Operationally, there was also little effort to work in an open and inclusive way. The possibilities of working in partnership with the local authority and the voluntary sector, not least through the social services and lay members, were largely ignored.

Secondly, the PCG did not have the resources, time or expertise to commit to PPI. Although the subgroup was consistently supported by an enthusiastic senior officer, she acknowledged that the PCG was in no position to take a lead locally in this work. In practice, this meant that each of the pieces of work which the PCG engaged in needed the support of someone beyond the organisation. Despite the resistance at board level to the strategic value of partnership, the practical approach of the subgroup was to look to others for help: the voluntary sector, the Gables PPG, the King's Fund, London Region, independent consultants.

Thirdly, the PCG lacked leadership in PPI work. Although the members of the public involvement subgroup were individually committed and enthusiastic, none of them were able or willing to turn the monthly discussions into a strategic process of action and change. On several occasions, a series of actions were identified at the end of the meetings, only for these to be forgotten by the next meeting when new ideas emerged or priorities shifted. This failure to always follow through, combined with falling attendance among the members, meant that the group's approach ended up being more opportunistic than strategic, although the shared sense of purpose prevented the meetings feeling arbitrary in their content.

Although these various constraints limited what the subgroup was able to do, its approach also reflected the wealth of experience, ideas and resources brought to the group by its members. In particular, the focus on primary care development was consistently sustained by the professional and lay members of the Gables PPG and the involvement of the voluntary sector in the research project depended on the commitment and contacts of the lay member.

The success of the Gables PPG may, however, have been too defining a model: it ensured that, initially at least, the promotion of patient involvement at practice level was very focussed on the PPG model. This may have been too ambitious. By contrast, the *Preparing Professionals for Partnership with the Public* training programme concentrated on much more basic aspects of the relationships between primary care staff and their patients.

Unusually (for the King's Fund study as a whole), the voluntary sector was never perceived to be problematic as a route to involvement – although it was largely ignored by the board members with no interest in either PPI or partnership work. In the subgroup, the voluntary sector was treated as being a valuable locus for engaging with patients and local people. Furthermore, the commitment to hearing the voices of people who had traditionally no voice in health policy was implemented through close collaboration with the voluntary sector, who took on a role as intermediaries in identifying participants for the study. Thus 'near' voices were not treated as potential obstacles to hearing more distant voices, but as partners in engaging with the whole community.

Making a difference

Although the members of the public involvement subgroup had a fairly clear idea of the kind of outcomes they wanted to achieve, they failed to think through all the issues of implementation. To an extent, they set sail in the right direction and hoped for the best.

This was most evident in the work to promote practice-level patient involvement work. There was lots of discussion at different times about the need for change, the potential obstacles, the opportunities and resources available and particular ways of promoting this work to primary care professionals. But these different discussions were never put together into a fully-considered assessment of what might actually be achievable with the resources available. In the event, the lay member and PPG chair were too under-resourced and unsupported to sustain a programme of development within practices with no tradition or experience of patient involvement. The obstacles were simply too great for their ambitions. The *Preparing Professionals for Partnership with the Public* training programme is designed to reduce these obstacles and may provide a more productive context for the development of this work.

Although the practice-based work looked to be a long haul, with profound changes in attitudes needed on the way, it was inspired by the on-going activity of the Gables PPG where outcomes were immediate. The chair and GP involved in the PPG were both clear that the task of the PPG was not principally to develop ideas for improvements in how the practice was run. Patient involvement in the PPG meant participating directly in a process of changing relationships and promoting community. This was most fully expressed in the annual Open Day. This gave patients an opportunity to interact with the practice professionals in an explicitly informal, friendly way, far from the usual professional-patient relationship. The key outcome of the Open Days was the development of a shared sense of community between professionals and local people, for which the 'level playing field' of the back garden (rather than the consulting room) was critical.

The health fairs run by Age Concern achieved similar direct impacts on local people. The attendance of primary care professionals in non-professional contexts familiar to older people was both an opportunity for health promotion and a chance to shift perceptions of professional-patient relationships.

Back at the PCG, any change was going to be a slow process. Nonetheless, the board members with an interest in patient and community voices persisted in questioning professional assumptions and in doing so forced the other members to at least recognise that lay and community voices might have a meaningful contribution to make to the development of the organisation and its services.

The agenda for the board always had a slot for feedback about the work of the public involvement subgroup, but other items on the agenda were treated as independent policy concerns. For example, the development of PCG policy on areas such as CHD and diabetes proceeded with little or no input from patient voices. Inevitably, the marginal role of the subgroup helped to ensure that PPI was kept marginal in the PCG's business.

The research project into the voices of vulnerable people illustrated the difficulties and opportunities of using involvement work to address cross-organisational concerns. It began as an idea in the subgroup; although the board was informed about it, they had no particular reason to buy into it. As a piece of work exploring patient and community perspectives on health and social care needs, the danger was that it would fail to connect with the institutional concerns of the PCG. Nonetheless, when it was published, the officer responsible for taking it forward felt that it was extremely well placed to be taken seriously by the new PCT. In particular, the new chief executive had a background in social services and the report was all about the need for integrated care; the new NSFs on older people and mental health had to be implemented and the report described the reality of local needs in these client groups; the NHS Plan made clear that the PCT had to listen more carefully to patient views and this intervention demonstrated that the organisation had the ability to do this. It remains to be seen how effectively these connections deliver change in practice, but the project demonstrated that, with imagination, grounded user perspectives can connect to the structural, service-side obsessions of NHS organisations.

Getting the details right

The Gables PPG. A key reason why the PPG flourished was its focus on relationships: the relationships between professionals and patients and the relationships of all those with a connection to the practice as members of a shared community. PPGs are often set up as mechanisms for the patients to inform the professionals about their practice and services, or as mechanisms for professionals to educate their patients; either way, there is an imbalance in the contribution of each role. By emphasising changes in relationships and the promotion of community, the Gables PPG ensured that everyone took a shared responsibility for making the PPG a success.

The vulnerability of dependency. The research project sought to listen to the voices of individuals and their carers who had significant needs and were therefore typically highly dependent on services. This proved to be a challenging task because their dependency made them very wary of speaking their minds. Real skill is needed to put people at ease, and to ensure confidentiality and independence. Some of those who are 'hardest to reach', or 'hardest to hear', are the people with the closest relationships to existing services.

Valuing institutional lay voices. The lay member brought to her role almost everything that could have been asked of her: detailed knowledge of the needs of local people; extensive influence and contacts within the voluntary sector; experience of listening to and advocating for patient interests; and knowledge and experience of how organisations and institutions work. Yet the PCG board failed even to acknowledge these resources, let alone value them. Crucially, when she first joined the board, she was not introduced properly or given a chance to explain what she had to offer. Simple procedural failings contributed to an institutional failing to value its human resources.

Dangers and obstacles

Marginalisation. The members of the public involvement subgroup were enthusiastic but their work was marginalised. An NHS organisation with no culture of PPI needs a locus for the development of this culture, but as soon as such a locus is created, it risks being identified as the place where the agenda is taken forward, thereby marginalising it further. This Catch 22 of public involvement work can only be broken when there is a shift in attitudes at board level to take seriously the implications of the work for the rest of the organisation. The change from PCG to PCT may provide such an opportunity.

Professional attitudes. The biggest obstacle faced by the members of the subgroup was the resistance of local primary care professionals to working in partnership with their patients and communities. The professional perception of patients as people with problems needing their intervention ensured that they and the communities they belonged to were not seen as resources for change, but insatiable sources of need.

Failures of communication and support within the NHS. If the PCG was never very interested in partnership across the health economy, it also suffered from a lack of internal support, particularly from the health authority. At each level, there was a failure to think about the interests and involvement of other parts of the institution. The subgroup was not supported by the PCG; the PCG was not supported by the health authority (at least in its PPI work). At each level, the interests of other parts of the system were ignored.

Doing it better

There was no formal commitment within the PCG to evaluating the implementation and impact of PPI initiatives. However, there were strong informal mechanisms. Above all, the openness and range of the discussions in the public involvement subgroup provided an opportunity for people with different connections to the organisation to reflect on their practice.

An early initiative, the 'Keeping Warm in Winter' health fair was discussed in some detail within the subgroup, principally because considerably fewer people turned up to the event than had been anticipated. Group members felt that the main problem had been the short notice and the inadequacy of the advertising for the event, which had otherwise gone off well. However, this initiative was a discreet event with a simple indicator of success: number of attendees. The more long term developmental work in primary care did not lend itself to such straightforward consideration. Nonetheless, the eagerness of the group to discuss their activity from all sides, i.e. to let everyone have their say from their own experience, meant that there was constant discussion of the problems and potential obstacles of all their ideas and activity. This informality and openness was both a strength and a weakness: there were plenty of opportunities to reflect on practice and experience, but this did not always translate into a fully thought-through approach the next time round.