



Royal College
of Nursing

Is policy translated into action?

A national survey undertaken by the Royal College of Nursing and Continence Foundation to examine how policy relating to the development of Integrated Continence Services in England is progressing

SUE THOMAS



ACKNOWLEDGEMENTS

I would like to express my thanks to all those who have given their time and enthusiasm in support of this study; to the steering group in particular to Prof. Kathy Getliffe, Dr. Judith Wardle, Dr. Adrian Wagg and the Royal College of Nursing Continence Care Forum

Special thanks must go to Debbie Rigby and Angela Billington without whose help I would never have managed to collect the data. To Peter Halton in Cornwall NHS Trust who was responsible for map production, to Janet Freeman for statistical support, Janine Sumnall for administrative support and to Philip Scullion and latterly Alison Bardsley who covered my work at the Royal College of Nursing.

Most importantly thanks go to all the Continence Nurse Specialists and staff in the Primary Care Organisations who completed the questionnaires and participated in telephone interviews. Without their cooperation this report would not have been possible.

My final thanks go to the Health Foundation who had the vision to see the potential benefits of this study for service development. They provided the funding that gave me the opportunity to take time out from my normal role to try and understand the difficulties that implementation of Government policy can bring so that I could start to develop, with others, solutions to help.

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FOREWORD

I am delighted to write this foreword, as the information gleaned by this survey will be invaluable to Primary Care Trusts and to primary care professionals alike. My initial major involvement in developing incontinence services was as co-author (one of the et al's!) of *Button, D., Roe, B et al (1998) Continence-promotion and management by primary health care teams. Consensus guidelines*. Whurr Publishers, London. The guidelines were evidence based and subsequently introduced at Castlefields Health Centre. The key messages from those recommendations are emphasised by this study-that incontinence is very common, mostly not reported and that services can often be improved by better utilisation and integration of existing resources. PCTs and all NHS services have many and valid calls on their resources, and improving continence services is one of these, not least as part of delivering the National Service Framework for Older People, an NHS priority. This publication will help us to focus on what is required and I strongly recommend it.

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AUTHOR FOREWORD

I must state at the outset that this study was undertaken to examine the extent to which the guidance published in '*Good Practice in Continence Services*' is being implemented. It was not undertaken as a randomised controlled trial or to be negative and highlight deficiencies in the implementation of policy. Many groups of professionals and patients have worked tirelessly over the last few years with the sole interest in improving continence care in the UK. The Government has responded with policy guidance and continence organisations and their supporters want change to take place.

Achieving change for a non-priority area like incontinence could not have been scheduled at a more difficult time as Primary Care Groups moved into Primary Care Trust status, Strategic Health Authorities were formed, new priorities were developed and new roles emerged. Service reorganisation and NHS priorities were inevitably the foremost thought within primary care.

Service reorganisation added to the complexity of administering the questionnaire but this survey was not just about discovering what was happening it was about making it happen. Throughout the survey considerable time has been spent in disseminating good practice and facilitation – to enable services to move forward and moving forward they are.

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EXECUTIVE SUMMARY

In 1998 the Royal College of Nursing Continence Care Forum and Continence Foundation with other continence stakeholders lobbied Government to introduce new national guidance for the reform of continence services in England. As a result of this lobbying 'Good Practice in Continence Services' (DoH 2000) was launched. This document 'Is policy translated into action?' explores the impact of this guidance in primary care. Based on surveys to primary care organisations and continence nurse specialists it presents an initial picture of the grass roots implementation of this policy.

Staff from five NHS regions participated in the survey. Hard copy structured questionnaires were circulated to all the Primary Care Organisations (PCOs) and Continence Nurse Specialists (CNS) in each region by post, one version for those working in PCOs and another for CNS.

With the exception of CNS in one region a telephone appointment was made to complete the questionnaire over the phone. This allowed for clarification of the information required and qualitative data to be obtained.

Data was recorded and PCO responses compared with responses given by CNS. Data was also compared against the PCOs Health Improvement and Modernisation Programme (HIMP) and Strategic Financial Framework (SaFF) documents.

In year two a shortened survey focusing on key implementation themes was repeated to PCOs. HIMP and SaFF documents for each PCO were examined with reference to continence services. Workshops to further understand development barriers in respect of implementation of the guidance were also held.

Findings reveal a network of highly qualified clinicians, continence nursing and therapy specialists who are moving continence services forward with their primary care colleagues but inevitably Government priorities take centre stage and competing demands in primary care have led to service development inertia in some areas. What needs to be recognised is that the proposals to ensure a modern continence service develops are largely organisational rather than dependent on large scale financial investment. Implementation will be successful with attention to basic issues.

The National Service Framework for Older People (2001) requires that Integrated Continence Services be developed by April 2004. At the current rate of development this will not be achieved but key areas for action could move services speedily towards this goal

KEY FINDINGS

- Awareness of the continence guidance has increased over the last two years. Only 1% of PCOs are not aware of this policy.
- 91% of PCOs have stated they have plans to develop ICS.
- Translating policy into action at a strategic level still needs to take place. 38% of PCOs have not yet discussed their plans at a PCO board level. Higher priority areas and lack of communication seem to be the most significant obstacles preventing this.
- 38% of PCOs now mention continence in their Local Development Plans.
- Only 8% of PCOs have plans to develop a Director of Continence Services, the element seen as central for pulling integrated continence services together. The main reservation appears to be the title Director.
- Incontinence can affect all ages. At the two ends of the age spectrum paediatric continence care and care of older people require greater attention:
- PCOs stated they had limited access to paediatric continence advisers. Only 10% of PCOs could state that children with difficulty maintaining continence were not being excluded from school.
- The launch of the free pads for nursing homes guidance brought greater focus onto containment of incontinence. Practice examples reveal no equity in the way the guidelines are being implemented.
- There is significant good practice in continence care which can be easily shared but dissemination routes need to be identified.

HOW CAN WE MOVE FORWARD?

- Development of a local continence Task Force to guide service modernisation.
- Identification of a 'named commissioner' to develop plans and lead service development forward at PCO level.
- Effective communication between primary, secondary and tertiary care services, with outside agencies, social services, educational authorities, care home providers and users and carers.
- Awareness that continence issues require higher profile within PCOs – particularly at Board level.
- A continence lead or Director of continence services developed in each ICS area.
- External facilitation to help with focusing on service commissioning.
- Formation of 'virtual' ICS teams to take forward development.
- Identification of new specialty leads for continence: geriatrician, paediatrician, coloproctologist etc.
- Inclusion of continence within Local Development Plans particularly with reference to NHS priority areas.
- Sharing good practice more effectively.

Part I Background

INTRODUCTION

Incontinence of urine and faeces is a major issue in healthcare today. Urinary incontinence in particular is extensively discussed in the literature, illustrating the magnitude of the problem. The financial cost is enormous: total incontinence-related expenditure for the UK was more than £420 million in 2002, with the NHS purchasing £80 million-worth of absorbent products alone (Euromonitor 1999).

But financial cost is only part of the equation. Incontinence also exacts a considerable cost in terms of patients' quality of life. Clearly, the impact will vary from individual to individual and be subject to environmental influences, making quantitative measurement difficult. However, by studying the effects of incontinence we can start to understand the burden it imposes and, in turn what health services individuals need to preserve a reasonable quality of life. Cure rates in excess of 50% are reported for several diagnostic categories where expert services are available (RCP 1995), suggesting that specialist continence services have a vital role to play in helping patients manage continence problems effectively.

A BRIEF BACKGROUND TO THE DEVELOPMENT OF CONTINENCE SERVICES

The concept of a comprehensive continence service is not new. In 1983 the King's Fund published a paper, *Action on incontinence: a multidisciplinary approach to continence promotion* which concluded that a comprehensive continence service would be an effective way of encouraging change and fostering good practice in continence services across district health authorities.

In 1991 the Department of Health carried out a major review of continence services, consulting widely with leading continence support groups and professionals in the field of continence care. Its report, *Agenda for action on continence services* (Sanderson 1991), reflected the views of both professionals and service users and offered a framework for continence service delivery. It concluded that the impetus to create better services needed to come from the centre, and that the need for good services was so urgent that local providers could not afford to wait for research findings on cost-effectiveness and best practice.

While acknowledging the value of such research, the report suggested that existing good practice could provide a useful framework for other services. It also made a strong case for accurate needs assessment as opposed to containment. A cost-efficiency comparison between carrying out a continence assessment and supplying disposable products showed the cost of containment to be ten times greater than that of assessment and subsequent management.

Rooker (1992) conducted a survey on continence policy and practice in England, focusing on the provision of services and aids to community patients. The report included responses from 86% of the country's district health authorities and described a 'continence lottery' for services based on location and raised concerns relating to assessment and the supply of disposable continence aids. One of the outcomes of the report was the introduction of free continence pads to patients in residential homes, which had a significant impact on health authority continence budgets.

From a commissioning perspective improving continence services was first identified as a purchasing priority in 1994 but it has been argued that no one wants to be responsible for providing continence services resulting in services frequently being neglected and at risk of marginalisation (Rhodes 1993).

To further raise the profile of continence services a multidisciplinary working party reviewed the implications for continence service provision, education and research and developed a guide for continence service delivery (RCP 1995). A comprehensive commissioning guide was also produced to assist with service development (Norton 1995).

Historically, continence services have been delivered in the community but the importance of initiating assessment in hospital is well recognised. Unfortunately, continence assessments have for too long been seen as little more than pad assessments that concentrate on product provision rather than on identifying and treating a problem, and on containment rather than continence promotion. This 'management model' was clearly recognized in 1999, when the Audit Commission used urinary incontinence as an indicator for examining the quality of patient assessment by district nurses. This audit highlighted the fact that although district nurses often completed comprehensive assessment documentation, this took the form of a prescriptive requirement for pads. Nurses often implemented a conservative care plan focusing on managing the problem rather than treating the underlying cause.

In 1998, Wigan and Bolton Health Authority published the results of Promoting Action on Clinical Effectiveness (PACE), a two year programme, which specifically addressed the issues of continence assessment, training and cost- effectiveness (Bradley & Morgan 1998). The project found that providing more training and education reduced spending on continence products by a quarter.

A similar study of a nurse-led continence promotion service in Glasgow concluded that employing a nurse dedicated to urinary incontinence in the community resulted in improved management, a greater level of awareness and resource savings due to correct and appropriate product use (McGhee al 1997).

As part of the NHS Executive strategy for clinical guidelines, in 1996 Button et al developed national continence guidelines that could be translated into local guidelines by purchasers and providers. Their methodology included a systematic review of the literature relating to incontinence. One of the main recommendations of the project was that there should be greater multidisciplinary education of all health professionals at pre- and post- registration levels in order to increase awareness of continence promotion. Equally importantly, the guidelines called for proactive management and provided a rationale for treatment interventions based on current evidence.

Norton (1995) and Roe et al (1996) also suggested that purchasers of continence services should not be confined to providing a clinical service for individuals and should have a broader remit of education, training and management.

This is the background that led up to the formation of an NHS Review Group on continence services and the publication of *Good practice in continence services* (DOH 2002) subsequently referred to as '*Good practice*'.

Good practice outlines a standard set of principles for improving health and tackling health inequalities in service provision for people with bladder and bowel dysfunction. In order to deliver effective continence care, the document calls for new ways of working and new partnerships, and sets out a proposal for an Integrated Continence Service (ICS) based on four levels of service provision.

INTEGRATED CONTINENCE SERVICE TARGETS

Figure 1.1: Integrated continence services



DoH. *Good Practice in Continence Services*. 2000

ICS targets

Good practice's aim is to set out a strategic direction for the modernisation of continence services. The guidance stated that:

'Services will extend to faecal as well as urinary incontinence, to children as well as adults and to people living at home, in hospital or in long-term care. They will cover prevention as well as treatment and management of incontinence with the heaviest responsibility for delivering appropriate continence services placed on primary care teams. A Continence Services Director will bring together, lead and co-ordinate all staff in primary, secondary and tertiary care services with outside agencies (social services, education authorities, care home providers, users and carers) to develop, agree and put into practice evidence-based policies, procedures and guidelines for continence care.'

The guidance also set out the following specific targets.

All services

Services provided by various professionals at different levels employed by different agencies should be organised in an integrated (collaborative) way. These professionals should:

- Work to common evidence-based policies, procedures, guidelines and care pathways to and from primary care and specialist services.
- Undertake group audit, review and research.
- Co-ordinate education activities.
- Promote continence.
- Provide initial assessment and first line treatment, i.e. practice or district nurses should carry out continence assessments, including physical examination of patients.

Primary health care and community teams

- Identify all people with incontinence.
- Offer appropriate assessments.
- Help carers understand the condition and treatment.
- Deliver first line services: i.e. each practice should have someone who is trained to undertake an informed continence assessment.
- Facilitate access to specialist services when appropriate.
- Carry out audits and share the results.

Health authorities and primary care trusts

- Ensure access to ICS for all patients who need it.
- Ensure access to investigative facilities and specialist services when needed.
- Collect information from primary/community teams for benchmarking and assessing/reviewing performance.

Joint targets for health and local authorities – children

- Ensure children are not excluded from normal pre-school and school education activities solely because they are incontinent.

Joint targets for health and local authorities – residential care and nursing homes

- Ensure that people with incontinence who require residential or home care are identified, assessed and appropriately managed and treated.

Targets for in-patient care

- Assess and manage in-patients who newly present with incontinence.
- Identify, assess, manage and treat patients with long-standing incontinence problems.
- Ensure that surgeons with relevant expertise only carry out surgical procedures.
- Identify patients with incontinence problems following treatment.

Special groups

The report also identifies a number of discrete groups for whom continence problems and access to specialist services may present problems. These include people with long term physical disability, neurological conditions, older people in residential and nursing homes, the homeless and prisoners.

SERVICE COMMISSIONING

Commissioning goes beyond purchasing episodes of care provided in hospitals. It is a strategic activity that focuses on developing services to meet the identified health and healthcare needs of local populations. Using the Service and Financial Framework (SaFF) to negotiate costs and activity can help ensure patients' needs are met. This forms a vital part of the design and review of services.

Over the last few years, the NHS has seen a rapid expansion in the number of PCOs. In 2002, health authorities merged into 28 Strategic Health Authorities (StHa), making PCOs the fulcrum of the local health economy. As well as undertaking a daunting range of functions including health improvement, primary care development and clinical governance, PCOs are now responsible for commissioning local health services including continence services.

Good practice recommends evidence-based policies, procedures, guidelines and targets for the establishment of ICS. These recommendations are backed up by other policies including the *Essence of Care standards* (DH 2001) and work carried out by the National Center for Health Outcomes Development.

Although *Good practice* sets out in detail what is required for continence services at each level of the NHS, the document was originally published as a statement of best practice and therefore does not prescribe mandatory actions for healthcare providers. This is regrettable: waiting lists and NSFs have helped create an environment where incontinence is not automatically high on local agendas. According to the report, the situation is further complicated by the taboo that still attaches to the condition, making individuals reluctant to come forward. People with the problem are therefore unlikely to lobby for better services at a local level.

Part 2 The Survey

The Royal College of Nursing and the Continence Foundation have carried out a two-year survey funded by the Health Foundation to measure the extent to which *Good practice* is being implemented. An advisory panel was set up to advise and comment at each stage. This report '*Is policy being translated into action?*' sets out the survey's findings.

METHODOLOGY

The tools for the survey were developed in consultation with continence care professionals drawn mainly from the Royal College of Nursing Continence Care Forum and the Continence Foundation. A steering group provided strategic, clinical and methodological guidance. The survey tools defined the relevant domains and criteria in the continence guidance within primary and secondary care settings. The draft tools were refined by the steering group before being piloted.

The survey focused on the following areas:

- Details of the respondent and the geographical area surveyed.
- The organisation and staffing, etc, of existing continence services (covering wherever possible the proposed service development areas from the new guidance).
- The respondent's knowledge of the new continence guidance.
- A record of any action taken at PCO level as a result of this knowledge.

As the policy only applies to England, the survey covered PCOs in England only. The Chief Executive of each PCO was asked to nominate someone within the organisation as 'lead person for continence'. Continence specialists were identified through the Continence Foundation directory.

Data was collected using hard copy structured questionnaires, one version for those working in PCO and another for continence specialists. These were posted to respondents and an appointment made to discuss and complete the questionnaire by telephone. The telephone interview enabled any aspects of the questionnaire that were unclear to be explained and gave the interviewee an opportunity to provide qualitative data. The call also acted as a reminder for respondents to participate in the survey. The hard copy questionnaire was the source of the data for analysis. The data was coded and then converted manually into centrally held computerised records. Double entry of data was used to minimize inconsistencies and errors.

The aim of the study was to collect data from each PCO and continence nurse specialist rather than a sample from the population in order to avoid any selection bias. By collecting data prospectively, the study was able to assess and reflect on current practice. The sheer number of PCOs in England combined with budget limitations meant it was impossible to examine all PCOs in each region. Therefore the following five regions were randomly selected:

- South-west.
- West Midlands.
- London.
- Trent.
- Northern & Yorkshire.

The South-west region was used as a pilot for the survey. Questionnaires were sent to all other PCOs and continence nurse specialists between September 2001 and August 2002 for year one of the survey. A shortened survey was repeated for year two between November 2002 and July 2003 to the same PCOs and a more qualitative, descriptive analysis was obtained of services. This was compared with the PCOs' Health Improvement and Modernisation Program (HIMP), Local Development Plan (LDP) and Strategic and Financial Framework (SAFF). Additionally at the request of respondents in two NHS regions, a feedback session on year one data

was held. At respondent request a further workshop was held focusing on how NHS priority areas could be used to get continence onto local agendas (see section 4 - Linking Integrated Continence Services into NHS priorities). For the other four regions surveyed one PCO was randomly selected from each and invited to attend a feedback and moving forward workshop. Three out of the four PCOs chosen accepted the invitation. This workshop was used for feedback but also for trying to elicit the tools that might be helpful to ensure continence moved forward in Local Delivery Plans (LDPs) in the future.

Figure 2.1: Regions surveyed



Figure 2.2: Sample of Primary Care Organisations surveyed

WEST MIDLANDS REGION



List of organisations surveyed in the West Midland Region

Birmingham 1 South East PCG. 2 South West PCG. 3 Greater Yardley and North East PCO. 4 Heart of Birmingham. 5 Hodge Hill PCG. 6 North PCG **Coventry** 7 East PCG. 8 North PCG. 9 West PCG **Dudley** 10 South PCG. 11 Beacon & Castle PCG **Herefordshire** 12 Herefordshire PCO. **N Staffordshire** 13 Central Stoke PCG. 14 Newcastle-Under-Lyme PC. 15 North Stoke PCO. 16 South Stoke PCO. 17 Staffordshire Moorlands PCG. 18 Burntwood Lichfield & Tamworth PCO, **S Staffordshire** 19 Cannock Chase PCG. 20 East Staffordshire PCG. 21 South Staffordshire PCG. 22 Stafford PCG. **Sandwell** 23 Oldbury & Smethwick PCG. 24 Rowley Regis & Tipton PCG. 25 Wednesbury & West Bromwich PCG. **Shropshire** 26 Shropshire County PCG. 27 Telford & Wrekin PCG. **Solihull** 28 Solihull PCO. **Walsall** 29 North Walsall PCG. 30 Walsall East PCG. 31 Walsall South PCG. 32 Walsall West PCG **Warwickshire** 33 Nuneaton & Bedworth PCG 34 Rugby PCG. 35 Rural North Warwickshire PCG. 36 Stratford & District PCG. 37 Warwick District PCG **Wolverhampton** 38 North East Wolverhampton PCG. 39 South West Wolverhampton PCG. 40 Wolverhampton South East PCG. **Worcestershire** 41 Bromsgrove & District PCG. 42 Malvern Hills PCG. 43 Redditch PCG. 44 Worcester City PCG. 45 Wychavon PCG. 46 Wyre Forest PCO

PROJECT MANAGEMENT

The project was managed and delivered by Sue Thomas, Nursing Policy Adviser at the Royal College of Nursing. A steering group was convened to provide clinical guidance, oversee the audit and advise the project lead on strategy, audit tool development, data analysis and preparation of the final report. Methodological and statistical support was also provided from other sources. The organisations represented on the steering group and those that supported the setting up of the survey are listed in Appendix 4.

ENSURING CO-OPERATION

The success of the audit depended on respondents completing the questionnaire, and every effort was made to secure the co-operation of individuals and organisations. Although the aim was to collect data from as many PCOs and continence nurse specialists as possible, the data will inevitably be subject to some selection bias. Many continence nurse specialists completed the questionnaires on behalf of a team of nurses. The final audit sample included data representing 204 PCOs and 200 continence nurse specialists from all five regions. The researcher is grateful to all the respondents who gave their time and effort to support the audit.

ETHICAL APPROVAL AND CONFIDENTIALITY

Two research ethics committees scrutinized the proposal. Both independently classified the project as an audit, which meant that no further ethical approval was needed. Anonymity was safeguarded using coded identifiers. The researcher stored the data.

SAMPLING

There were two sample groups within the target population:

- The sample of PCOs.
- The sample of continence services via continence nurse specialists.

Figure 2.3:
Total numbers of PCO interviews in survey Year 1

Total PCOs in sample regions	Questionnaires circulated	Interviews undertaken	Percentage response
204	204	153	75%

Figure 2.4:
Total numbers of PCO interviews in survey Year 2

Total PCOs in sample regions	Questionnaires circulated	Interviews undertaken	Percentage response
204	204	138	68%

In year two there had been significant change in organisational status as Primary Care Groups (PCGs) moved to Primary Care Trust (PCO) status, either independently or through merger with other PCGs. Strategic Health Authorities were formed and there was also some geographical movement of NHS regions. This presented some difficulties with new PCOs becoming part of the new regions. To maintain continuity questionnaire administration was limited to those organisations that were part of the year one survey.

A further report for publication in 2004 will give details of the findings from the survey to Continence Advisers.

Part 3 Results

Good practice made recommendations for modernising continence services in four key areas:

- Service commissioning.
- Service delivery.
- Service organisation.
- Tools to Improve service provision.

Milestones for the implementation of these recommendations were set out in the Department of Health's National Service Framework for Older People (DOH)

- April 2003 – HIMPs and other relevant local plans should have included the development of an ICS.
- April 2004 – all local health and social care systems should have established an ICS.
- April 2005 – compliance with the single assessment process (SAP).

SERVICE COMMISSIONING

The survey revealed a national network of highly qualified continence advisers and interested clinicians that wish to modernise England's inequitable continence services and provide first-rate, comprehensive services for all. Some PCOs have made a concerted effort to review and develop services but action is still needed at both local and national level to improve continence management in the UK. The programme of work to develop local ICS has generally been led by key stakeholders in continence service delivery although some PCOs have been particularly proactive. Stakeholders – usually continence service professionals like urologists, gynaecologists and continence nurse advisers – have formed local continence task forces to spearhead development. The ICS target within the NSF for Older People has ensured that geriatricians have become increasingly interested in development but despite this the main aim of the guidance, to develop ICS throughout England, is still in its infancy.

The key drivers for change are partnerships between current continence services, PCOs, local authorities, social services departments and users and carers. Without effective communication between these groups, ICS will be impossible.

Awareness of the need for change

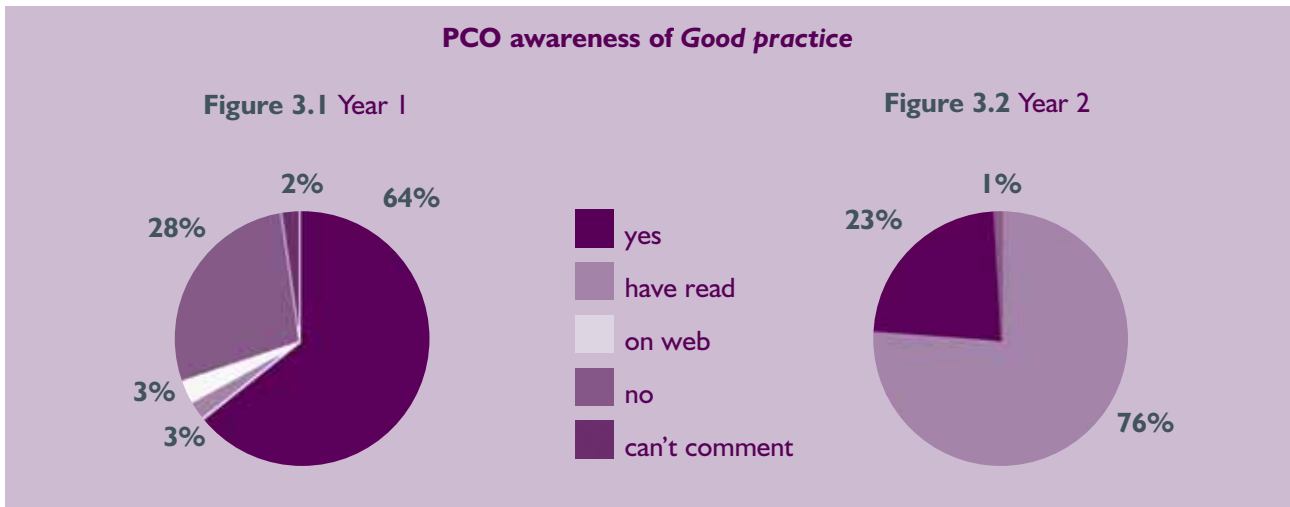
In order to implement Good Practice, PCOs must be aware both of current policy for continence and the need to modernise continence services. We therefore asked them whether they had a copy of Good practice, and whether they were aware of its recommendations.

Good practice: Integrated Continence Service

Development can start with the enthusiasm of team members. Becky Willcox a urology nurse specialist /continence adviser at Gloucestershire Royal Hospital is a member of Intacon, a working group formed to spearhead implementation of Good practice. Gloucestershire has a population of 562,000 with the continence needs of the population being met by three different health trusts working in isolation from each other. Each individual continence service had its own way of working which evolved over time. Clinical care was of a high quality but did not ensure equitable services for the people of Gloucestershire. Intacon was formed from a multidisciplinary group the purpose to develop and integrated and equitable approach to care. Similar groups have developed in other areas.

*Becky Willcox and the Intacon team
Gloucester*

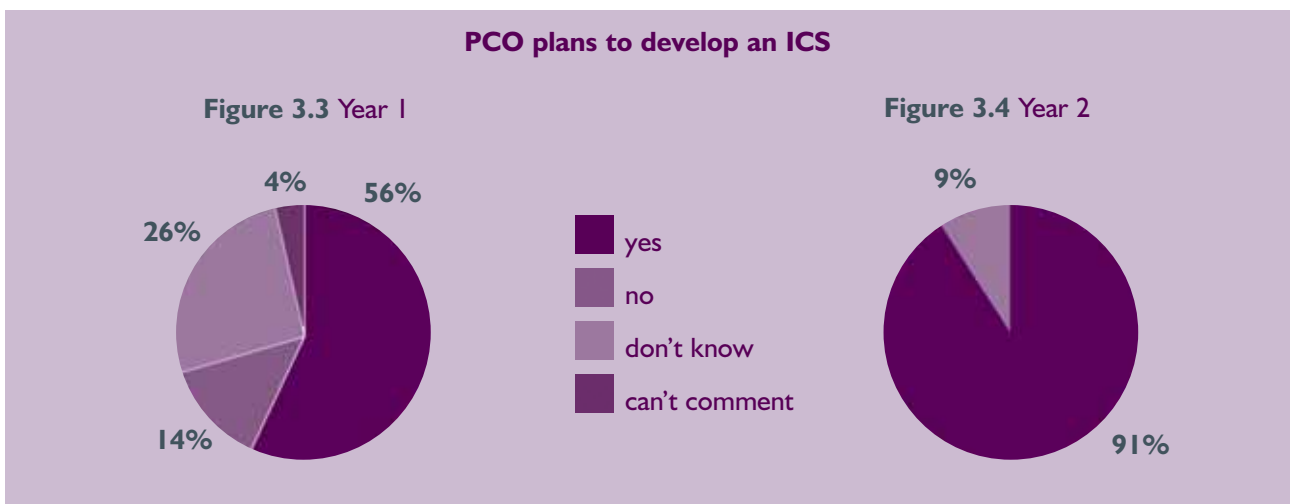
Figure 3.1 and Figure 3.2: Question “Do you have a copy of Good practice, and are you aware of its recommendations?”



In year one overall, 64% of PCOs interviewed said they had a copy of the document and an additional 6% had either read it or seen it on the Department of Health website. However, nearly a third of respondents did not have a copy or were unable to respond to this question.

In year two of the survey the situation has changed significantly. 99% of respondents had read the guidance either by having a copy of their own (23%) or reading it via the DH website (76%). Only 1% of PCO's has no knowledge of the guidance. This may be attributed to the fact that the *NSF for Older People* included within its standards the development of ICS. This NSF has raised significant awareness and provided targets for service delivery.

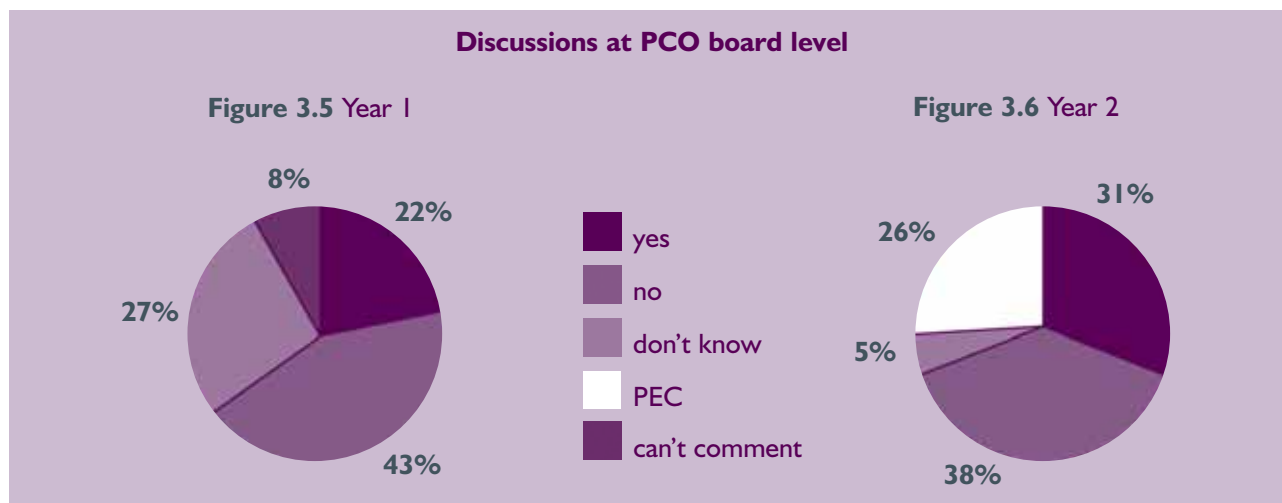
Figure 3.3 and Figure 3.4: Question “Does your PCOs have plans to develop an ICS?”



Throughout the survey knowledge of the guidance and interest in developing ICS has increased. In response to the question does your PCO have plans to develop an ICS in year one 56% of respondents said yes, 14% said no and 26% replied don't know whilst 4% could not comment.

In year two 91% of the PCOs interviewed stated that they had plans to develop and ICS.

Figure: 3.5 and 3.6: Question “Does your PCO have plans to develop an ICS?”



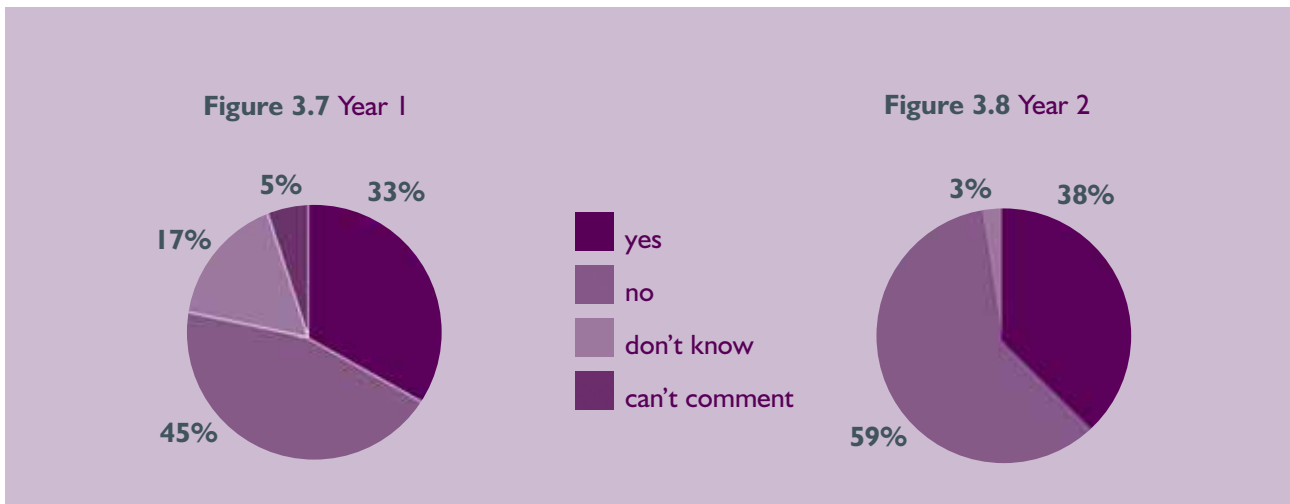
Implementing the guidance requires strategic action. In year one although 56% of the organisations surveyed said they had plans to develop an ICS, only 22% had discussed their plans at PCO board level. The remainder either had not discussed plans (43%) did not know if plans had been discussed (27%) or could not comment (8%).

In year two 91% of the PCOs interviewed stated that they had plans to develop an ICS but on closer questioning not all appeared to have discussed this major development for commissioning and implementation at a strategic level. There was some improvement with 31% of PCO's stating they had discussed the development of an ICS at Board level in comparison to 22% the previous year. Increasingly continence services were being discussed by the PCO Professional Executive Committee (PEC) (26%) which had not occurred in Year 1 of the study. This appears to indicate a raised awareness of continence issues

PCOs are faced with the prospect of implementing an enormous amount of wide-ranging NHS policy. Staff working within continence services need to develop their political awareness in order to get relevant issues on to the local commissioning agenda and to make sure that adequate time is being allocated for continence to be discussed. The ability to influence at strategic level is critical at a time when we are working to develop services that meet the needs of people with bladder and bowel dysfunction. Failure to modernise and redesign continence services now is arguably a waste of the efforts made by those stakeholders who have lobbied to improve continence services. Effective commissioning is critical for success.

Much more needs to be done to engage PCOs in continence service development and more effort is required to develop relationships between specialist continence teams and PCOs. In particular, more needs to be done to increase the strategic contribution of continence advisers at PCO board level. Many continence advisers said they felt excluded from decision-making, and that they lacked influence at PCO board level. The question of how continence services could open up an effective dialogue with PCOs was frequently raised.

Figure: 3.7 and 3.8: Question “Do HIMPs cover the development of an ICS?” (Year 2 Local Development Plans)



Government health plans and the Health Improvement and Modernisation Programme (HIMP)

Standards within the *NSF for Older People* required PCOs to have a plan for developing ICS in place by April 2003 and integration of services by April 2004. Changes in service commissioning also require trusts to produce a local development plan (LDP) outlining their commissioning plans for the next three years.

PCOs need to address key targets within the NHS Plan, the Cancer Plan and the NSF. Although continence is not identified as a specific priority in the NHS plan, it does form a key part of several priority areas and is a requirement of the *NSF for Older People* (as indicated above). Poorly managed incontinence often leads to inappropriate hospital or long-term care admission, delayed discharge and blocked hospital beds.

In year 1 only one-third of PCOs surveyed said that continence was currently mentioned in their HIMP, and this was confirmed by subsequent scrutiny of HIMP and SaFF plans. PCOs that had included continence within their HIMP had done so for a variety of reasons, not necessarily to promote ICS. These reasons included:

- Providing more continence education and training.
- Assessing the cost or provision of continence products.
- Being a lead PCO for continence services locally.
- Working towards a NSF target.

In Year 2, 38% of PCOs had continence specifically mentioned within their Local Development Plans.

To ensure the development of an ICS within PCOs it is critical that the way continence impacts on the NHS priority agenda is identified to individual PCOs.

Good practice: developing expertise

Bournemouth PCO continence team serves the whole of East Dorset. The team consists of five specialist nurses, each of whom has a distinct role to play in integrating continence services. The continence service is fully hosted by Bournemouth PCO. Integration service team meetings began in November 2001, involving representatives from the PCO board and all professionals involved in continence service delivery including gynaecologists, elderly care physicians, urologists, physiotherapists, GPs and the Trust planning team. The clinical governance lead joined the team at a later stage.

Individual continence nurse specialists have taken the lead on specific service strands. This means they are recognised for the work they do and that they can establish an area of expertise that will benefit service integration. The team appointed a Director of continence services in January 2003.

Angela Billington Continence Services Director Bournemouth

Good practice: 'Putting the patient first'

An established multidisciplinary continence interest group in Bath is continuing to work towards closer integration. Led by a continence nurse specialist and a consultant geriatrician, 'Putting the patient first' has repeated a service mapping exercise which was first carried out in 2000, extended patient audit over a wider area and established communications between primary and secondary care with the aim of integrating their continence services.

Marlene Powell Continence Advisor & Dr Bruno Bubna-Kasteliz Geriatrician Bath

SERVICE DELIVERY

Good practice highlighted existing problems with continence services

- Lack of policy focus for continence promotion
- Poor identification of sufferers
- Lack of involvement of users at all levels of planning and service delivery
- Geographical variations in:
 - Eligibility of services
 - The range and quantities of treatment provided and the time spent waiting
 - The numbers of staff trained in continence assessment and management

There are numerous examples throughout the country of good evidence based practice in continence services (Continence Foundation 2002) but there is still a geographical variation in service delivery and lack of integration between primary and secondary care. More sharing of best practice and benchmarking of services is required. Excellent tools like *Essence of Care* (DoH 2001) have been developed for benchmarking. Problems exist in the areas that have been deemed to require particular priority for example older people.

Targets outlined in *Good Practice* still need further development for equity of service provision. For example more work is required with paediatric services and older people's services:

Joint targets for health and local authorities: children (*Good Practice* p22).

Although many PCOs felt they had excellent paediatric services closer questioning revealed that services had been developed in isolation with little evidence of a child-centered approach or integration. There was poor or no access to paediatric continence advisers and care given did not follow national guidelines. There was also no benchmarking against best practice and an ignorance of the support children might need. For example a study in Sheffield found a strong association between bedwetting and bullying in schools (Williams 1996) and it is highly likely that children with daytime continence problems will experience even greater social isolation as this is a more 'visible problem' with their peer group.

This lack of awareness is further substantiated by a survey undertaken in 2003 by the Children's Continence Action Group (Modernisation Agency 2003 in press)

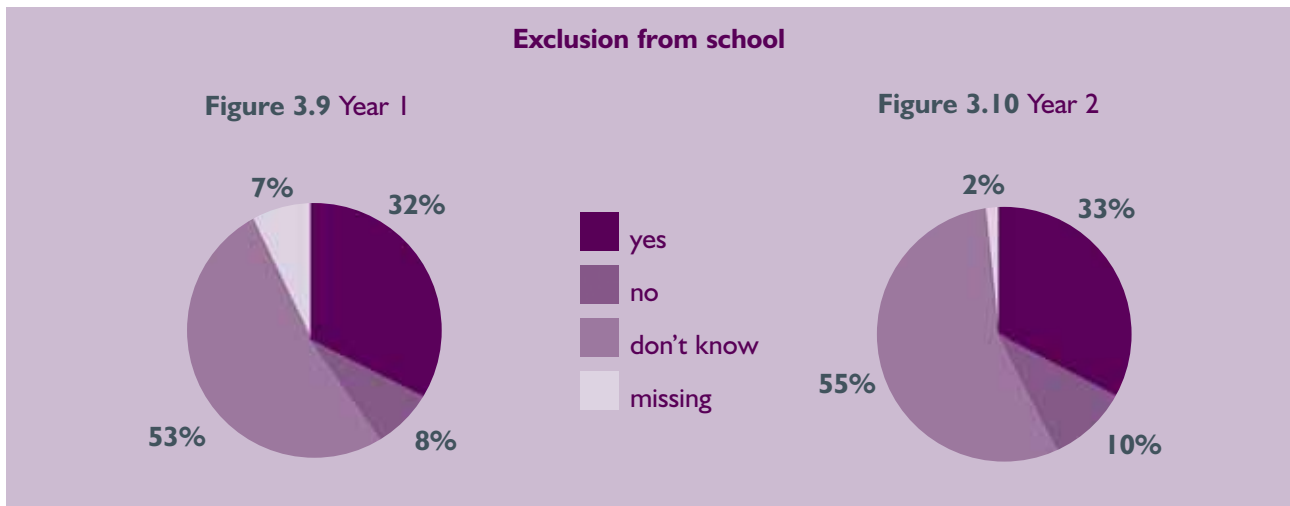
Good practice: Open referral community continence clinics for children

An open referral community continence clinic is run jointly in Sheffield by the paediatric continence adviser and consultant community paediatrician. They also have input from a clinical psychologist and dietician. Information regarding the clinic is given to parents in the Accident and Emergency Department of the Children's Hospital when a child presents with severe constipation

Dr Ursula Butler Sheffield Children's Trust

Primary care organisations were asked if children were being excluded from school because of problems maintaining continence.

Figure 3.9 and 3.10: Question “Are children being excluded from school?”



In year one of the survey 32% of respondents felt that children were being excluded from school due to problems maintaining continence. Only 8% of PCOs could state that children were not being excluded from school and 60% of PCOs were not able to answer the question. Many respondents on questioning said they simply had not thought of this as an issue.

In year two the situation was very similar with 33% feeling that children were being excluded, 10% sure they were not prevented from attending and 55% not having sufficient knowledge to answer the question.

Good practice: Promoting healthy bladder and bowels in schools

Many children do not drink enough during the school day - and this contributes to a number of short and long-term health problems. In conjunction with the Royal College of Paediatrics and Child Health the Enuresis Resource and Information Centre (ERIC) carried out a survey of drinking facilities in primary and secondary schools in two education districts. The results revealed that drinking facilities and access to water in many British schools were highly unsatisfactory.

Enuresis, Resource and Information Centre Bristol

Although continence is not a target in the NSF for Children, all aspects of childcare and healthcare are now receiving much wider attention. A suite of documents were published in September 2003 which include *Keeping Children Safe* – the Government response to the Victoria Climbié Inquiry Report, Youth Justice- next steps, as well as the Social Exclusion Unit’s report on the education of ‘looked after’ children.

Good practice: A public health approach to health bladder and bowels

A multidisciplinary team has developed WaterWise Guidance for Schools in Warrington which links to the Water is Cool programme by the Enuresis Resource and Information Centre (ERIC). This programme encourages schools to provide children with extra water to drink during the daytime in an effort to promote healthy bladder and bowels

Warrington, Primary Care Trust

The Department for Education and Skills Green paper *Every Child Matters* (2003) sets out plans on how the Government will achieve five key outcomes that are essential for children and young peoples well being. The first of these is ‘Being healthy: enjoying good physical and mental health and living a healthy lifestyle. This consultation document may be a useful lever in the future for ensuring children’s continence services are part of the PCO LDP.

Good practice: Access to continence supplies

All children with continence problems are seen and assessed by a paediatric continence adviser. Advice is given on promoting continence through healthy bladder and bowels. The child’s suitability for toilet training is assessed before any pad provision is made.

Julia Jeffries Paediatric Continence Adviser Bedfordshire

Additionally lobbying to focus greater public awareness on the needs for children bladder and bowel health is being undertaken at a national level by ERIC and in late 2003 the Modernisation Agency launched benchmarking standards for children’s continence management. Attention to this area should result in improved practice.

Joint targets for health and local authorities: residential care and nursing homes (Good Practice p 24)

There was evidence during the survey to suggest that the continence needs of older people living in residential and nursing homes were not being met equitably. Indeed further policy guidance released during the time of the survey for free continence pads in nursing homes to residents produced a negative effect on continence assessment and management. From October 2001 the Government responding to the Royal Commission on Long term care, implemented changes in funding care for people in care homes in England and is meeting the costs of registered nursing time spent on providing, delegating and supervising care in any setting. This is happening through a multidisciplinary – single assessment process (SAP). The Government also stated that all care home residents would be eligible for free continence products requiring NHS Trusts to provide these into Nursing Homes from April 2003. Trusts are required to move away from payments to homes to the provision of products following an initial assessment. The key principles for the provision of products (DOH 2000) are:

- Pads only after initial assessment
- Full range of products available
- Supply of products should be governed by clinical need
- Needs are regularly reviewed

Good Practice: Addressing two tier services

The nurse consultant in continence care in Cornwall suspected that there was a two-tier service in her area: that levels of care depended on whether people lived in their own home or in a care home. In the community there was an emphasis on screening, assessment, diagnosis and treatment but residents in care homes were managed with body worn products as first line treatment. The Workforce Development Confederation supported the bid she made to appoint a continence education facilitator for care homes. The expected outcome is that nurses working within care homes will be able to properly identify assess and treat incontinent patients using a common assessment process.

Sharon Eustace Consultant Nurse Continence Care West of Cornwall PCO

As part of the *NSF for Older people*, a single assessment process (SAP) must be in place across health and social care agencies by April 2005. This should enable all agencies to work together for the benefit of patients, reduce duplication and ensure effective co-ordination of assessment and care planning so that older people receive the right service - including continence services - in the right place at the right time. Clearly, this is a positive step for patients.

Good practice contains specific targets for residential and nursing homes recognizing the major problem of incontinence within this sector: 1 in 3 residential home residents are incontinent of urine as are nearly 2 in every 3 nursing home residents. The prevalence in nursing homes of regular faecal incontinence is also around 1 in 4 (DOH 2002).

The eligibility for free continence products succeeded in bringing containment back to the top of the continence agenda. This guidance moved the focus away from continence promotion and the development of an assessment-led service. In the survey PCO respondent discussions about service delivery for older people were dominated by references to continence management with pad provision.

The Single Assessment Process (SAP) could help to overcome the problem addressing and directing support for the management of incontinence in older people, although this will only be effective if assessors are trained adequately and if they are free to act on the results of the assessment.

Looking at practice: Highlighting deficiencies in care homes

A survey by a continence adviser of 38 care homes in the Midlands highlighted the deficiencies in continence care provided by staff. In the homes 75% of residents were incontinent and the costs of disposable products were almost £250,000 per year. Severity of the incontinence was not recorded or monitored and there was no record of the rationale behind why mostly pads were being chosen as the management option and why other options had not been tried.

Janet Blannin Continence Adviser Bristol

There is currently no national standard for assessing continence but such an assessment could be triggered by questions on continence status in the SAP. As the SAP will be monitored by Strategic Health Authorities, PCOs will be required to assess continence effectively which could in theory help improve the continence management of older people.

The current lack of care home beds and the pressure on hospitals to discharge patients into the community has placed pressure on care homes to accept more dependent residents who may well be incontinent. In many cases staff in care homes may not be trained to provide appropriate care that patients with continence problems may require.

Looking at practice: The value of continence education

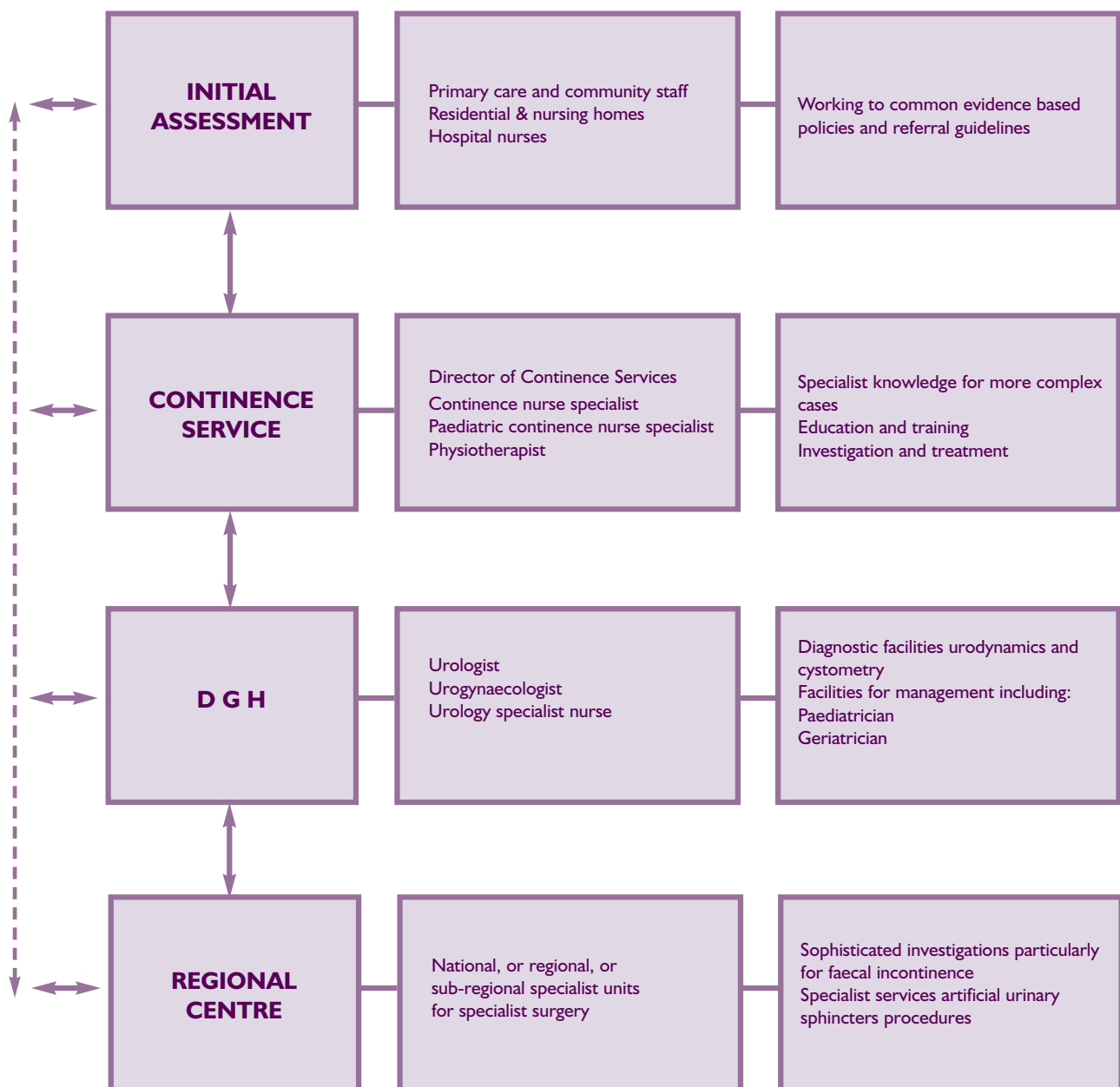
A snapshot survey in Rugby highlighted the overall incidence of urinary incontinence in nursing homes to be 63%. Despite the fact that 24 hour nursing care was available for toileting assistance, patients in some homes were wearing large, absorbent, very expensive pads. Regular free continence education was provided to both trained nurses and care assistants but uptake for this was not good because of other priority demands placed on staff. Homes where nurses and carers had received continence training had a lower incidence of incontinence indicating a vital need for education for all

Judith Shaw Continence Adviser Rugby

SERVICE ORGANISATION

Good practice stated that continence services provided for a specific population should be organized as Integrated Continence Services.

Fig 3.11 Integrated Continence Services



High-quality continence care requires a multidisciplinary team approach that crosses the primary and secondary care interface. Specialist continence team members will include continence specialist nurses and physiotherapists, urologists, obstetricians and gynecologists. Care at this level will require contributions from other specialists such as coloproctologists, geriatricians and pediatricians, midwives and occupational therapists and the involvement of PCOs, GPs, district nurses, practice nurses and health visitors. Other team members will include social services, nursing and residential home carers, the voluntary sector, patients and carers.

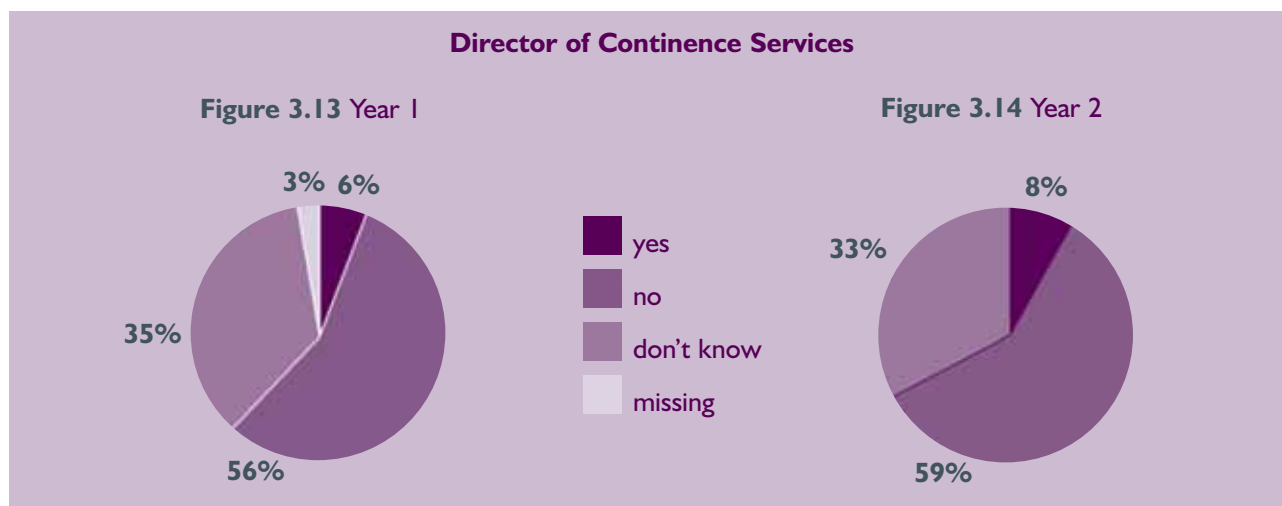
Figure 3.12: Continence services team



Such a disparate team requires a senior team leader or Director who is capable of team building, promoting the continence service at both Trust Board and Strategic Health Authority level, and developing clear links with social services and the independent care home sector. This team leader is then supported by a specialist continence team to form the ICS. The ideal ICS would span several PCOs and the leader would need to have access to the PCT board (see also appendix 3).

Appointing a Director of Continence Services

Figure 3.13 and 3.14 Question: “Do PCOs plan to appoint a Director of Continence Services?”



Good practice suggested that appointing Director of Continence Services was a central element in moving ICS forward. However, in Year one only 6% of PCOs surveyed were planning to appoint a Director. More than half (56%) said they had no plans to appoint a Director, while over a third did not know. In Year 2 still only 8% of PCOs felt they would appoint a Director, 59% (more than in the previous year) would not appoint and 33% still did not know.

The main reasons PCOs gave for not appointing a Continence Director were the connotations attached to the job title itself and funding. Only one of the PCOs surveyed in year one did not have a problem with the title ‘Director’. The remaining PCOs surveyed frequently stated that the term Director implied an executive role, and felt that if they appointed a Director for one service they would be put under pressure to appoint them in other areas too. Respondents also said it would be difficult to stretch existing funding to cover a Director’s salary.

At the time of interviews in year one two regions that had successfully bid for funding for a ‘continence lead’ had had their funding reduced, forcing them to make alternative arrangements.

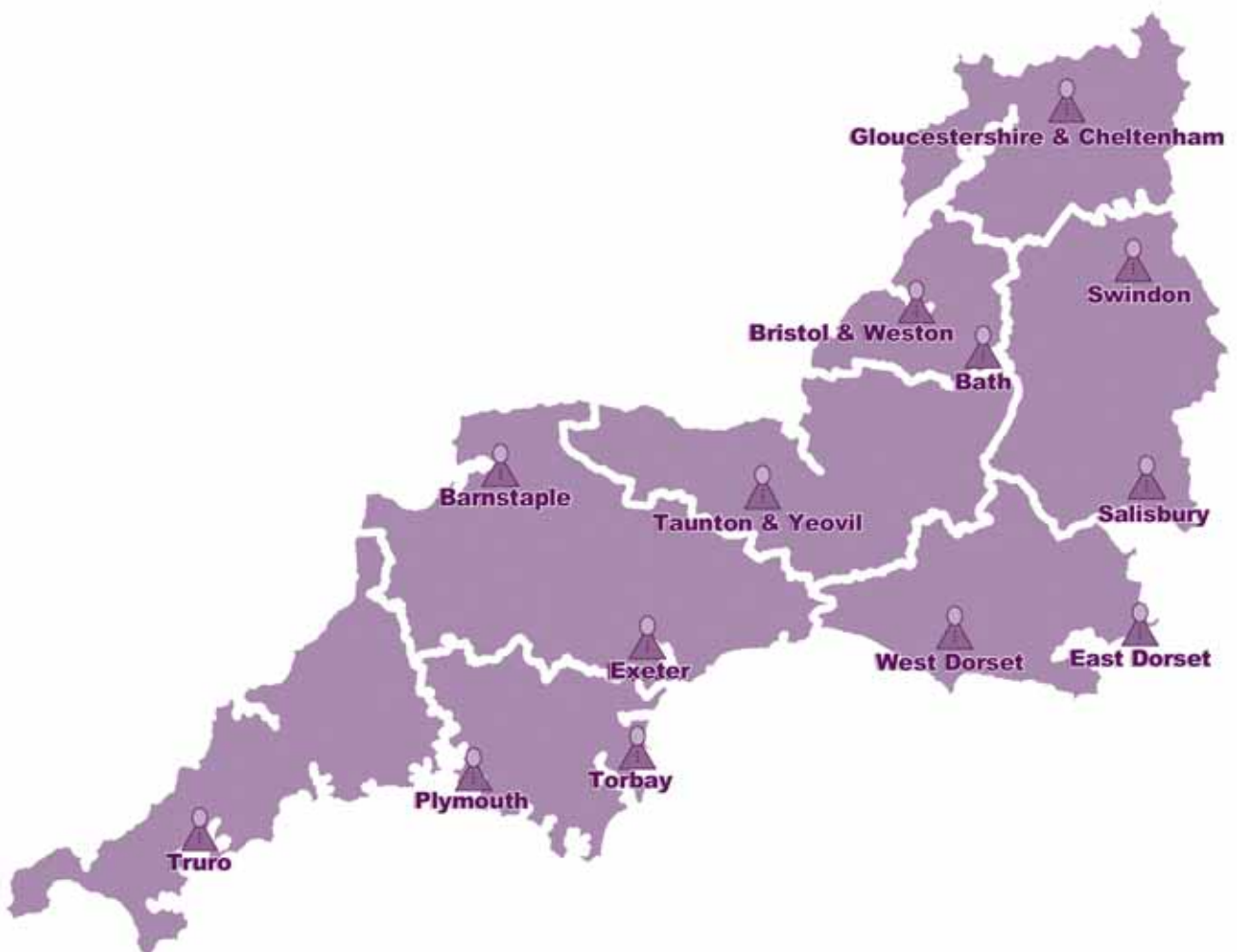
Several continence advisers felt that their existing specialist role encompassed the responsibilities of a Director. However, these specialists were also managing a clinical workload. Modernising Continence Services requires the Director to:

- Work in partnership with all stakeholders.
- Adopt a higher profile within the organisation.
- Get fully involved in all stages of the commissioning process.
- Be included in all organisational and service evaluations.
- Be involved in commissioning, board and executive work.

A Director should also have the personal authority to ensure that their knowledge, experience, ideas and values are respected and acted upon. Without protected time to undertake these activities it would be difficult for continence specialists to juggle their clinical and managerial functions. There may be an argument for reconsidering the job title, but the role and functions of a ‘Director’ should be viewed as a priority and time and funding allocated to one person or a group in order to make sure they are carried out.

Prior to April 2003, by which time PCOs should have had plans in place for the development of ICS, only three of the regions surveyed had developed a lead post for a proposed integrated service. Of these three areas, only one used the title 'Director'; the other two areas had appointed continence clinical lead posts. A suggested way forward for encouraging service organisation is for continence services to identify where their ICS should be located and the relevant members of the continence care team (see fig 3.12). This 'virtual' ICS could then approach PCOs with a "ready made package" for developing ICS (Abrams cited in Thomas 2002).

Fig: 3.15 'Virtual' Integrated Continence Services in the South West



The number of continence adviser posts in the UK rose from 521 in 2000 to 551 in 2002 but the survey shows that multidisciplinary continence teams feel there are still inequalities in continence provider provision to PCOs, particularly for physiotherapists, paediatric continence advisers and advisers with an

interest in ethnic minority clients.

A small percentage of continence nurse specialists surveyed did not have access to computerized data collection systems or clerical support (other than for pad distribution). Such support could increase overall service efficiency.

Good practice: The advantages of a multi-disciplinary continence advisory team

The Chorley and South Ribble PCO Continence Advisory Service is the first service in the UK to bring together nursing, occupational therapy and physiotherapy professionals in a truly integrated continence advisory service.

A multidisciplinary continence team project started in September 2000, working closely with the Trust clinical audit team. This audit identified the need for additional occupational and physiotherapy resources.

The innovative nature of this teams work has been described in several professional nursing and therapy journals (Pomfret 2001, Vickerman 2001)

Ian Pomfret, Nurse Continence Advisor; Julie Vickermann, Continence Occupational Therapist; Clare Howden, Continence Physiotherapist, Chorley and Ribble PCO.

Good practice emphasizes the need to 'ensure users and carers are involved in the planning, provision and audit of services'. For the most part, this is not yet happening – 69% of respondents stated in year 1

that there was no consultation with service users, although a significant number said they were currently considering ways of implementing this.

Good practice: user groups

A continence nurse specialist in Wandsworth made a successful bid for HIMP funds to establish Continence Service User Groups. Three groups have been set up so far: an Asian women's group; a group for older people, including those with physical disabilities; and a group for physically disabled younger people. These have all been developed in conjunction with a project worker who speaks Urdu and Punjabi, and who has also established links with the local MS society and Carers' Association. InContact was cited as a useful resource for facilitating the involvement of users at a local level.

Heather Young Wandsworth Primary Care Trust

TOOLS TO IMPROVE SERVICE PROVISION

Good practice identified a variety of management tools which would be useful in improving the delivery of continence services:

- Care pathways
- Audit packages
- Performance indicators

Increasing numbers of respondents in year 2 mentioned that they were benchmarking their services using the Department of Health’s *Essence of Care* tool which includes measures aimed at building on and improving existing continence services.

Good practice: Benchmarking

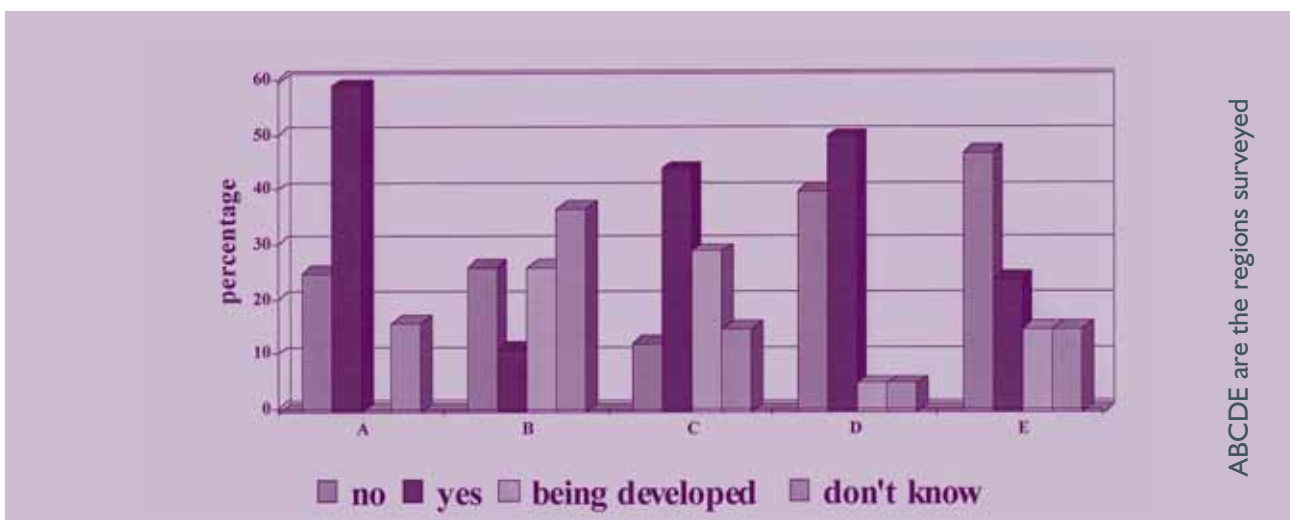
The Children’s Continence Action Group in association with the National Coordinator of the *Essence of Care* National Nursing Leadership Programme has illustrated how *Essence of Care* can be used as a benchmarking tool in paediatric continence promotion.

June Rodgers Paediatric Nurse Adviser Liverpool

Continence care pathways

Care pathways are a vital component of efficient continence services. There are many useful examples already available which can be adapted to meet local service requirements. Many areas have produced standardized referral/advice and treatment pathways but these need to be more easily accessible, perhaps via the World Wide Web.

Figure 3.17: Question: “Has your area established care pathways?” Year 1



Discussion on the type of care pathways and services that used them identified that pathways tended to exist mainly between urology and gynaecology services and to a much lesser extent in primary care and priority groups like older people. Very few areas had developed pathways with social services departments.

Good practice: Developing continence care in partnership with social services

Incontinence can often be a precipitating factor in admission to residential or nursing homes. A pilot project in Nottingham has involved training, environmental audit and action planning to improve links with social services. The aims of the project included

- Video training and support for social care staff in identifying and managing continence problems.
- Continence clinics within day, residential and transitional rehabilitation centres and the Indian day centre.
- Raising continence awareness with clients and carers through information and support sessions.
- Assessment and care planning partnerships with patients and care staff.
- Environmental audits.
- Development of written guidelines.
- A link worker scheme.
- Written information for clients.

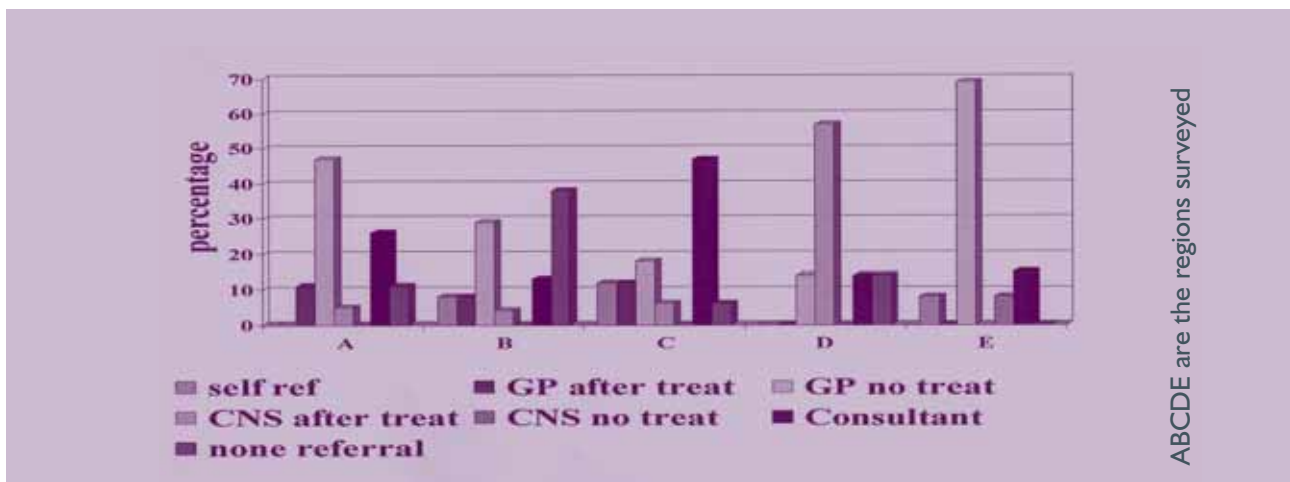
Under a linked pilot scheme, an Asian co-worker was also appointed. A clinic was set up in the Indian day centre, and culturally appropriate information and education given to service users and carers and for the future existing provision will be extended to cover learning disabilities services.

Sue Brown, Continence Nurse Specialist, Nottingham

Lack of care pathways and treatment guidelines at a local level has implications for secondary care workload. The Audit Commission report *First assessment* (1999) reported that 'In practice district nurses implement a conservative plan focused on managing the problem rather than treating the underlying cause'. In this survey the most common referral route to continence services was via GPs, who did not undertake patient assessment or

treatment but referred on directly to both primary and secondary care continence nurse specialists. This increases pressure on specialist services, in particular on secondary care services, and also stops patients getting immediate help to cope with their incontinence. This runs contrary to the recommendations set out in *Good practice* which indicate that primary care should be the first level of care for people with incontinence.

Fig 3.18: Question "How do patients reach the continence service?" Year 1



Service organisation - qualitative analysis

Throughout the study there has been enormous enthusiasm from both continence services respondents and Primary Care Organisations. One of the repeated requests made during completion of the questionnaires was for more help in achieving integration through workshops, facilitation to identify the steps needed to be taken to move services forward and for tools to assist with developing plans to present to the PCO Professional Executive Committee or Board.

In year two one PCO was randomly selected from each of the regions surveyed and asked if they would like to attend a feedback and moving forward session to explore in depth what support their PCOs might need to move towards an ICS. Four out of the five PCOs invited attended for a full day workshop, three members from each PCO participated. At least one member was requested to be a representative from the continence services team and another senior PCO representative. The structure of the day was semi formal with presentations recapping on the continence guidance and individual PCO group work on 'where they were' in terms of ICS development. There was discussion about what was needed to move forward.

In summary the main 'needs' raised from these workshops can be classified into four areas

- Highlighting how continence fits into the national agenda
- Help with mapping existing services
- How to develop business plans for development of ICS services
- Identification of continence leads

Additionally the groups stated that external facilitation to help with the planning process would be a valuable aid to focus attention on to what steps were needed to progress the guidance. Further work on designing tools to aid implementation has already been undertaken by the Continence Foundation and more work on disseminating this as an aid to ICS development would be helpful.

Part 4 Moving Forward

LINKING INTEGRATED CONTINENCE SERVICES TO NATIONAL NHS PRIORITIES

This survey has clearly demonstrated that although attention is being given to the development of ICS the emphasis is not as great as it might be if continence was a health and social care priority area.

The Government has stated that the "NHS Plan will deliver for the people of the country a health service fit for the 21st century with services designed around the needs of patients and improved health outcomes, particularly for the poorest in our society. Similarly the aims for social care are to improve services, promote independence and well being, and protect and support the most vulnerable" (DOH 2003)

The priorities

Based on the Department of Health's *Improvement, Expansion and Reform the next three years Priorities and Planning Framework 2003 – 2006* key drivers for primary care organisations are:

- Waiting, booking and choice
- National Service frameworks
- Financial balance

Each Primary Care Trust has responsibilities it must meet:

- To assess the needs of the population
- Ensure there is a local delivery plan for each NHS Trust
- Produce a local delivery plan for primary care and managed services
- Complete national output schemes
- Agree and monitor service level agreements

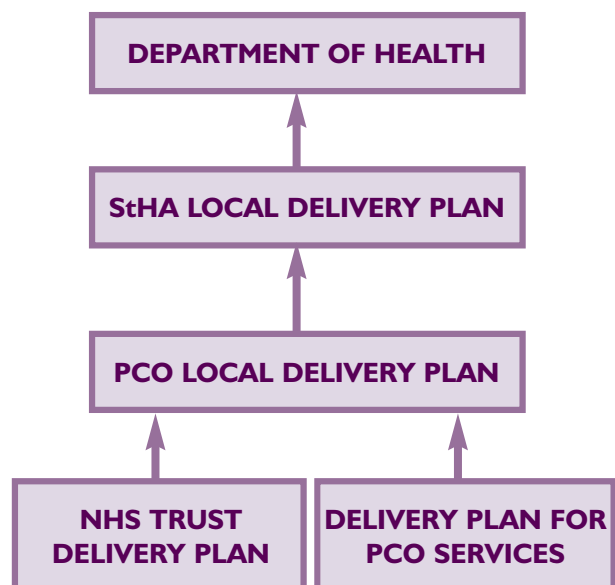
To influence change it may be beneficial to look at how the Government priorities are being developed and move continence forward through the priorities framework.

Service priorities

- improving access to all services through:
 - better emergency care
 - reduced waiting, increased booking for appointments and admission and more choice for patients
- Improving services and outcomes in:
 - Cancer
 - Coronary heart disease
 - Mental health
 - Older people
 - Improving life chances for children
- Improving the overall experience of patients
- Reducing health inequalities
- Reducing drug misuse

Although not mentioned specifically, continence links directly into almost all of these NHS priorities and examples of good practice for this exist (Continence Foundation 2000) an example of Good practice follows on the next 2 pages:

Fig 4.1: The planning and commissioning process



The following three pages illustrate a good practice example from Rowena Lavender, Continence nurse specialist East Elmbridge and Mid Surrey PCT and Dr Roger Walker Consultant urologist Epsom & St Helier NHS Trust.

Good Practice: Waiting booking and choice

Reduced waiting, increased booking for appointments and admission, more choice for patients and improving the overall experience of patients are two Government priorities. These targets were addressed by the Integrated Continence Forum (ICF) from East Elmbridge and Mid Surrey PCT. The Forum itself developed to move their continence services towards Integration and in the process identified that the female referral pathway to specialist continence services was complex.

Many female patients were seeing several professionals before getting the help they needed. Some of the female clients were dissatisfied with both the number of appointments needed and the time that was spent in the ‘system’ before their continence problem was thoroughly addressed. In some cases it was possible for a client to be referred

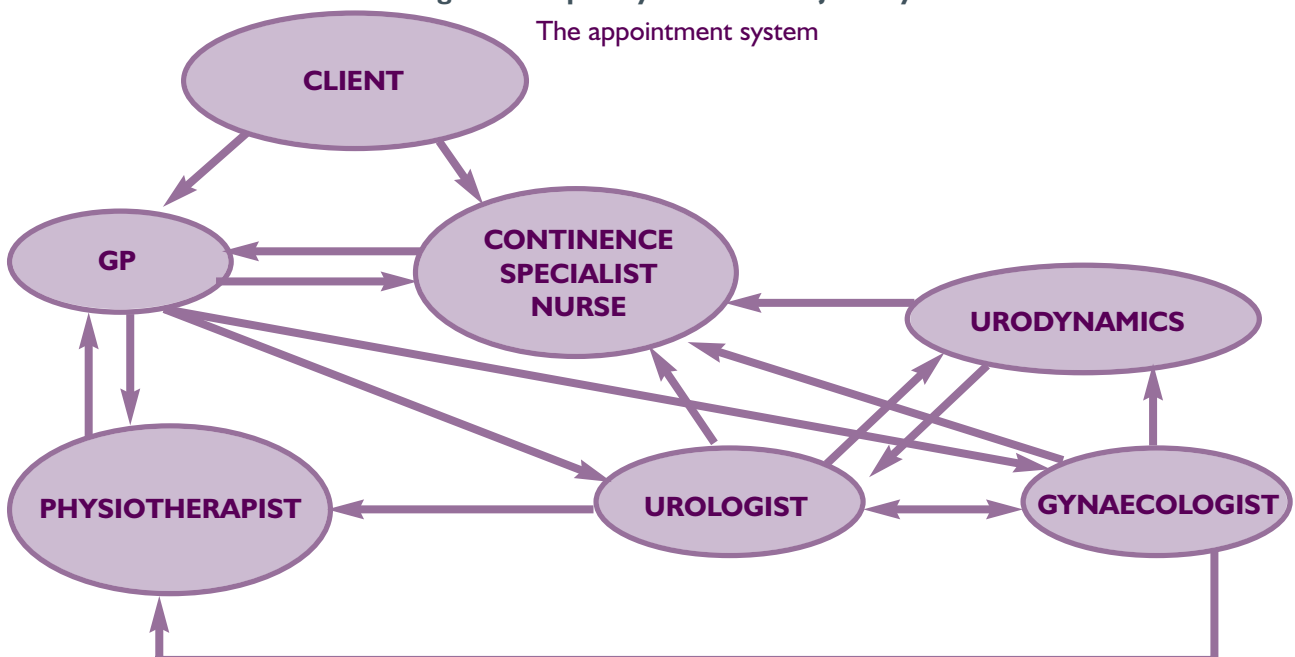
to the physiotherapy department, gynecologist and urologist as well as to the continence service for the same problem. Multiple referrals and an unclear referral pathway were problematic for two main reasons: -

1. Duplication of appointments for the client was time consuming
2. Poor use of already overstretched NHS resources resulted in poor efficacy and cost effectiveness.

A project ‘Simplifying the Client Journey for Females with Urinary Incontinence’ emerged, the need came from anecdotal comments from clients and reflection from practitioners. The project commenced during 2001, prior to significant organizational change with the Continence Service moving from being part of a joint Acute Community Trust to a PCO in April 2002. This formal separation from units such as Urology was potentially problematic. A simple mapping exercise of the client journey was identified with the points at which duplication and delay arose documented.

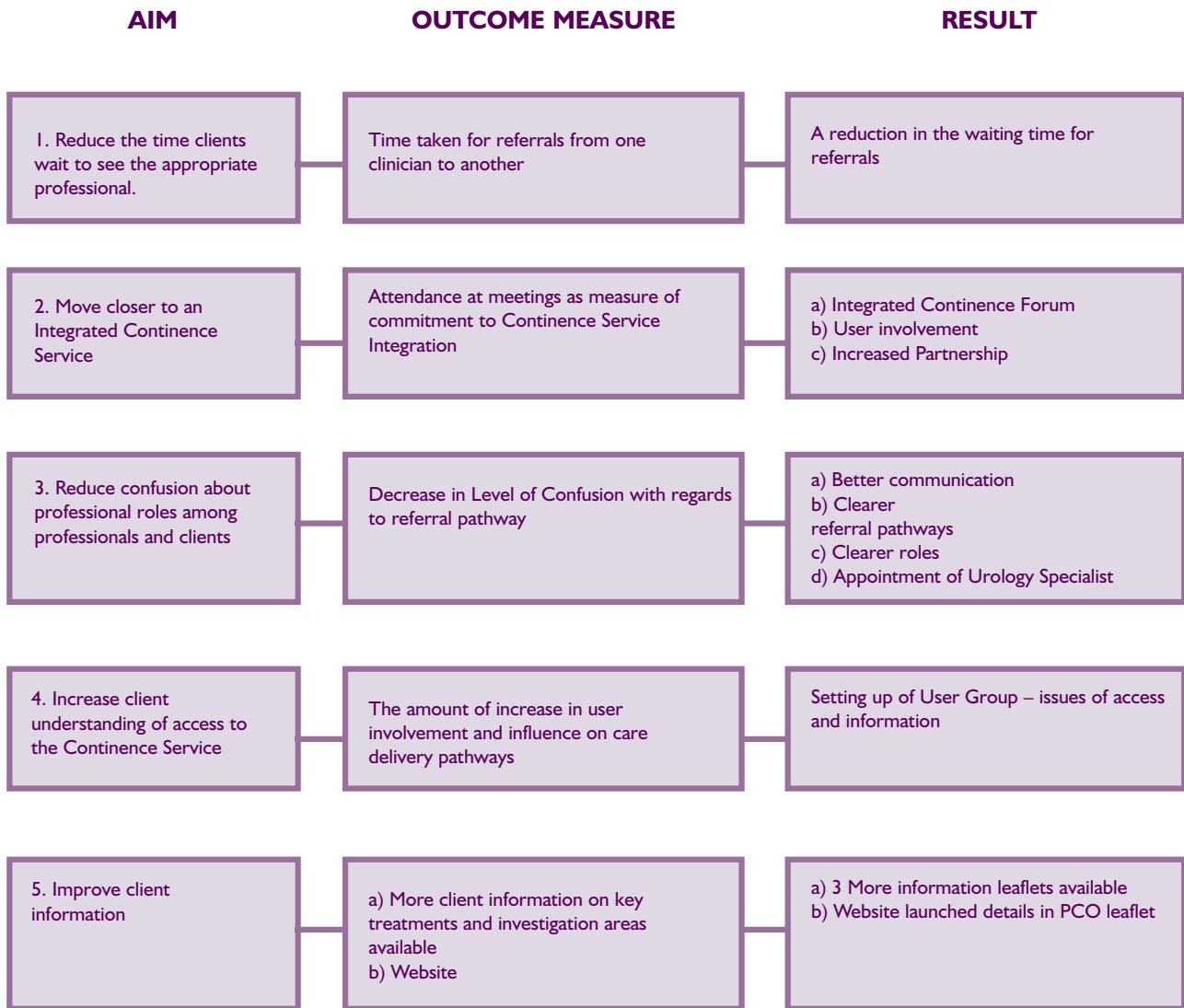
Fig 4.2 Complexity of the client journey

The appointment system



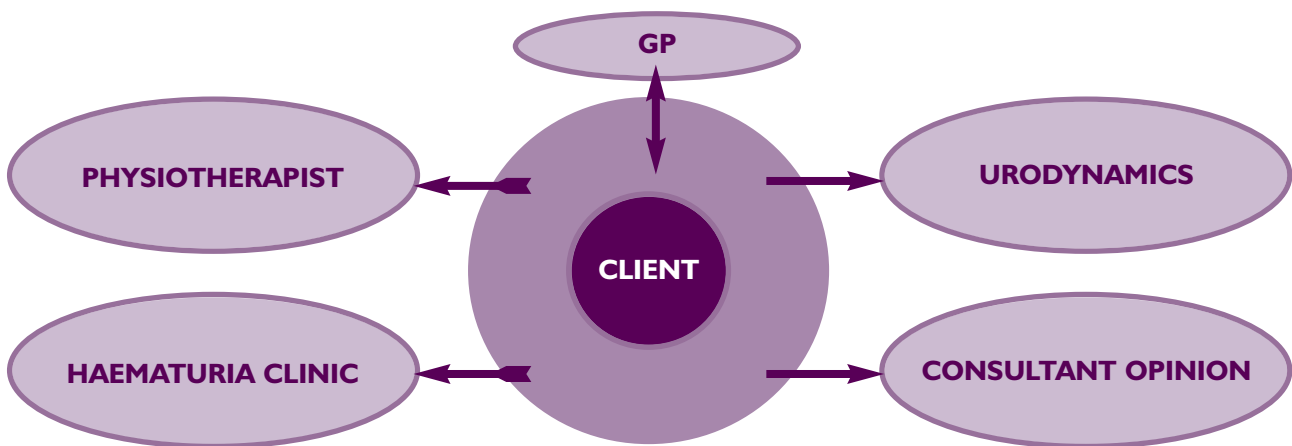
Once sticking points had been identified an improved client journey resulted.

Fig 4.3 Aims and Outcome Measures from the Project



The end result has been a clear referral pathway which has attracted national interest and first prize in the British Pharmaceuticals Best Practice Awards 2003. No additional resources were needed for the project. The old and new appointment system has produced dramatic improvements for patients.

Figure 4.4 Clearer Referral Pathways



The information and diagrams are reproduced with kind permission from Rowena Lavender Senior Continence Adviser East Elmbridge and Mid Surry PCT main author of the work

Good practice: The National Service Frameworks – Older people

In year two of the study when a more qualitative investigation of the barriers to implementation was undertaken the links between falls and urinary incontinence were explored with a number of PCOs and continence advisers.

Falls and bone health has a Standard within the NSF for Older people. The NSF Milestones in relation to this standard are:

- April 2003 Health, social services and the independent sector should have audited their procedures and put in place risk management procedures to reduce the risk of older people falling
- April 2004 The HIMP and other relevant local plans should include the development of an integrated falls service
- April 2005 All local health and social service systems should have an established service

The National Institute for Clinical Excellence has additionally been asked to produce guidelines on falls prevention by 2004 and osteoporosis prevention by 2005. It is also undertaking an appraisal on osteoporosis drug treatments. These guidelines and the appraisal will be very significant in the development of falls services.

Good practice: Interactive continence and falls training

An interactive training program for medical, nursing and multidisciplinary team members has been developed. These offer easy access insight into management of incontinence and falls.

Dr Peter Overstall Consultant Geriatrician Hereford

Where does continence fit with falls?

Overactive bladder leads to increased diurnal and nocturnal voiding that prompts rushing to the bathroom to avoid incontinent episodes. This can produce an increased risk of falls and fractures by necessitating multiple urgent trips to the bathroom, especially during the night. Nocturia increases the risk of falling because of sudden change in position; need to locate the bathroom quickly, and low or absent lighting (Capezuti, et al, 1999) Further causes of increased risk are due to slipping on urine and also through getting out of bed because the bed is wet. Evidence (Brown et al 2000, Luukinen et al 1996, Tinetti et al 1995, Tromp et al 2001) suggests that identification and treatment of incontinence would be an effective means of reducing the risk of falls and fractures in the elderly.

Given the physical and emotional burden that falls and fractures in the elderly place on both patients and their carers the inclusion of effective management strategies following the recommendations of the Good Continence Guidelines should be employed by Primary Care Trusts. Effective implementation of such strategies can then impact on Intermediate care and on bed blocking through fractures.

Good practice: Preventing Falls & Promoting Independence project.

One of the main objectives of a scheme developed by Merton, Sutton and Wandsworth Health Authority was to provide evidence based exercise opportunities across the community, linking with primary, intermediate & residential care to prevent hospital admission.

The project is targeted at people aged over 65 who have a history of falls or who, because of poor mobility and/or strength, lack confidence and have balance problems. Patients such as this can typically fall if they get up to the toilet at night.

Merton, Sutton and Wandsworth Health Authority

CONCLUSION

There has clearly been much progress since the publication of Good Practice in 2000 but the clock is ticking and by April 2004 all PCOs should have in place an ICS. This survey has show what enormous enthusiasm exists and that there is a real will to make things happen but ICS are only one small part of the current NHS agenda.

Changes are occurring as a result of Good Practice and other policy documents, in particular the *NSF* for Older people and the *Essence of Care* benchmarking standards. This should continue to drive the agenda forward. Given the fundamental nature of the organisational changes now under way, the main priority must be to ensure that appropriate arrangements are in place to maintain progress towards developing ICS in each area. It is imperative that there is communication between PCOs and continence services and that the networks currently lobbying for ICS are supported and maintained.

Simple steps can be taken towards encouraging integration:

- Establish a local continence task force (if this has not already happened) to identify action to support the implementation of ICS.
- Consider best practice and means of dissemination.
- Set up regional networks to:
 - share learning;
 - improve co-ordination
 - address development priorities.
- Form a virtual ICS (i.e. identify all the people who would form part of such a service), identify a Director; designate specialists and start approaching PCOs with proposals aimed at realising the ICS and moving the continence agenda forward.

Suggested action points for Continence Service team members

- Map out existing continence services.
- Identify Professional Executive Committee (PEC) and board members and consider how staff can work effectively with them and other key stakeholders to improve continence service delivery.
- Identify and get involved with local clinical networks and commissioning team members.
- Work with the public health team to collate data relevant to continence services.
- Be prepared to challenge local decision-making. You will need to be aware of understand current local and national priorities.
- Develop influencing skills.
- Public involvement is an essential part of the NHS Plan. Modernisation means working closely with local service users.
- More work needs to be done on developing simple tools to assist Continence Services and PCOs to take proposals forward on how to link continence into the priorities agenda.

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Help with Meeting Milestones for Primary Care Trusts:

Integrated Continence Services; Good, Better and Best Practice . A facilitated meeting to help with service planning for integrated continence services

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Appendix I

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Rotherham

June Rogers MBE, Director, Promocon

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Appendix 2

November 2003

Survey of Care Homes

During the course of this study such was RCN Continence Forums concern about the over emphasis on continence products that the RCN Independent Sector Adviser and Chair of the Continence Care Forum agreed to examine this issue further. A snapshot survey of care home managers and continence advisors was undertaken to explore how individual NHS Trusts are implementing the free pads guidance (RCN 2003).

Forty-six care homes, and ten continence services, returned questionnaires, and highlighted variances in the way in which Trusts have interpreted the DoH requirements. Although the majority were aware of the changes to product provision many were unaware of how their local trust will provide products in the future.

Three quarters of care homes surveyed had access to specialist continence advice provided by company nurses or from continence advisors provided by community trusts.

The majority of staff undertaking continence assessments were not employed within continence specialist teams, some had no continence training

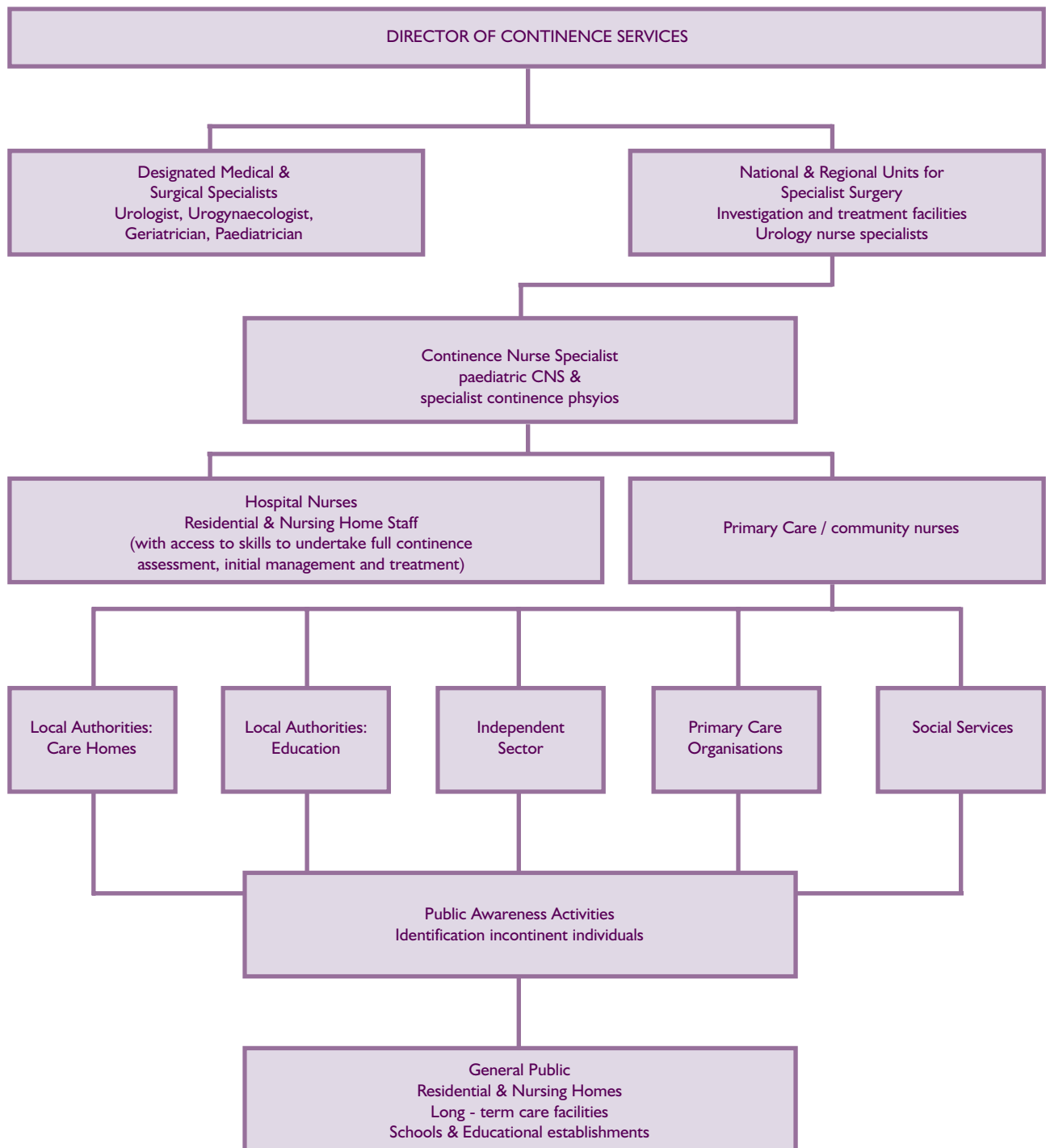
In twenty percent of homes, no evidence of a “continence assessment” was required by the Trust. Homes were provided with payments, based on a tick box of “urinary” incontinence or “double” incontinence, on the RNCC funding criteria. Where this occurred care home staff had no access to training and education on continence assessment and treatment, and do not have access to the local Continence advisory service. The impact on service users from this sample was from the variations it is clear there was no equity in the way in which the free pads guidelines are being implemented this is resulting in some clients living within care homes not being given access to specialist assessment, treatment and advice. This provides an inequitable service to clients residing in their own homes.

Prevention and identification of symptoms may be missed if comprehensive assessments are not undertaken, this may lead to clients not being offered treatment and possible cure for their incontinence problems. Many clients may be wearing incontinence products unnecessarily, leading to loss of dignity and increased costs.

Where homes do not have access to specialist support, alternatives to incontinence pads such as sheath systems may not be considered, also leading to a loss of dignity, independence and self-esteem for many people. Where care home staff have no access to training and education they may not be able to offer the best treatment, advice and care for patients. This situation clearly requires further consideration.

Appendix 3

Example model of Intergrated Continence Services



Participating Organisations

The following organisations and their Continence Nurse Specialists were invited to participate in this study. Service reorganisation resulted in several of these PCO's merging but all are mentioned for inclusion.

South West

Bath PCG, Greater Wansdyke PCG, Bristol N PCG, Bristol S & W PCG, Cheltenham & Tewkesbury PCG, Stroud & Berkeley Vale PCG, Cotswold PCG, Ridgeway Downs PCG, N Wiltshire & Devizes PCG, N Somerset PCG, Severnvalle PCG, SE Gloucester PCG, S Wiltshire PCG, Swindon PCG, Gloucestershire & S Tewkesbury PCG, Forest of Dean PCG, W Wiltshire PCG, Mendip PCG, Poole Bay PCO, Poole Central & North PCO, Somerset PCG, S Somerset PCG, W Dorset PCG, Weymouth & Portland PCG, Christchurch PCG, NE Dorset & Purbeck PCG, Taunton & Area PCG, Carrick PCO, Restormel PCG, E Devon PCG, Exeter PCG, Mid Devon PCG, N & E Cornwall PCG, E Cornwall PCG, N Cornwall PCG, N Devon PCG, Teignbridge PCG, West of Cornwall PCG

London

N Barnet PCG, S Barnet PCG, W Barnet PCG, N Camden PCG, S Camden PCG, Edmonton PCG, Enfield N PCG, Enfield Southgate PCG, Tottenham PCG, W Haringey PCG, N Islington PCG, S Islington PCG, Barking PCG, Dagenham PCG, Chingford, Wanstead & Woodford PCG, City & Hackney PCG, Hornchurch PCG, Romford PCG, Upminster PCG, Newham PCG, Redbridge PCG, Tower Hamlets PCG, Walthamstow, Leyton & Leytonstone PCG, Brent Central PCG, Brent N, S Brent, Acton & Central Ealing PCG, Northolt & Greenford PCG, Southall & W Ealing, Hammersmith & Fulham PCG, Harrow E & Kingsbury PCG, Harrow W PCG, N Hillingdon PCG, W Drayton & Uxbridge PCG, Brentford, Chiswick & Isleworth PCG, Feltham PCG, Hounslow PCG, Kensington & Chelsea PCG, Westminster PCG, Bexley PCG, Beckenham & Penge PCG, Bromley PCG, Orpington PCG, Greenwich PCG, N Lambeth PCG, S Lambeth PCG, N Lewisham PCG, S Lewisham PCG, N Southwark PCG, S Southwark PCG, Central Croydon PCG, N Croydon PCG, S Croydon PCG, Kingston PCG, Teddington, Twickenham & Hamptons PCO, Richmond PCG, Nelson & W Merton PCO, Battersea PCG, Putney & Roehampton PCG, Balham PCG, Tooting & Wandsworth PCG

West Midlands

Dudley: Beacon & Castle PCG, Dudley S PCG, Hodge Hill PCG, Birmingham Greater Yardley PCO, Heart of Birmingham PCG, N Birmingham PCG, Oldbury & Smethwick PCG, Rowley Regis & Tipton PCG, SE Birmingham PCG, Birmingham SW PCG, NW Walsall PCG, Walsall S & E, Wednesbury & W Bromwich PCG, Wolverhampton SE PCG, NE Wolverhampton PCG, SW Wolverhampton PCG, Coventry E PCG, Coventry N PCG, Coventry W PCG, Nuneaton & Bedworth PCG, Rural N Warwickshire PCG, Bromsgrove District PCG, Redditch PCG, Rugby PCG, Warwick District PCG, Stratford & District PCG, Malvern Hills PCG, Wychavon PCG, Worcester City PCG, Wyre Forest PCG, Burntwood & Lichfield PCG, Tamworth PCG, Cannock Chase PCG, E Staffordshire PCG, Newcastle under Lyme PCG, Central Stoke PCG, Shropshire County PCG, Central Stoke PCG, Stafford PCG, S Staffordshire PCG, Staffordshire Moorlands PCG, Telford & Wrekin PCG

Trent

Charnwood & NW Leicestershire PCT, Charnwood & NW Leicestershire PCT - North Charnwood Division, Charnwood & NW Leicestershire PCT - NW Leicestershire Division, Charnwood & NW Leicestershire PCT - South Charnwood Division, Daventry & S Northants PCT, Eastern Leicester PCT, Hinckley & Bosworth PCT, Hinckley & Bosworth PCT - Hinckley & Bosworth Division, Leicester City West PCT, Melton, Rutland & Harborough PCT, Northampton PCT, Northampton PCT - Northampton Commissioning Division, Northamptonshire Heartlands PCT, Northamptonshire Heartlands PCT - Corby Division, Northamptonshire Heartlands PCT - Kettering Division, Northamptonshire Heartlands PCT - Nene Valley Division, Northamptonshire Heartlands PCT - Wellingborough Division, S Leicestershire PCT, S Leicestershire PCT - Blaby & Lutterworth Division, S Leicestershire PCT - Oadby & Wigston Division, South Yorkshire HA, Barnsley PCT, Barnsley PCT - East Division, Barnsley PCT - West Division, Doncaster Central PCT, Doncaster East PCT, Doncaster West PCT, North Sheffield PCT, Rotherham PCT, Rotherham PCT - Rother Valley Division, Rotherham PCT - Rotherham Division, Rotherham PCT - Wentworth Division, Sheffield SW PCT, Sheffield W PCT, Sheffield E PCT, Trent HA, Amber Valley PCT, Ashfield PCT, Bassetlaw PCT, Broxtowe & Hucknall PCT, Central Derby PCT, Chesterfield PCT, Derbyshire Dales & South Derbyshire PCT, Derbyshire Dales & South Derbyshire PCT - Derbyshire Dales & South Derbyshire Division, Eastern Lincolnshire PCT, Eastern Lincolnshire PCT - Boston & Skegness Division, Eastern Lincolnshire PCT - East Lindsey Division, Eastern Lincolnshire PCT - South Holland Division, Erewash PCT, Gedling PCT, Greater Derby PCT, High Peak & Dales PCT, High Peak & Dales PCT - High Peak & Dales Division, Lincolnshire SW PCT, Mansfield District PCT, Newark & Sherwood PCT, NE Derbyshire PCT, Nottingham City PCT, Rushcliffe PCT, West Lincolnshire PCT

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