

Continence Foundation

GOOD, BETTER AND BEST PRACTICE

In 1998 a working group was set up by the Parliamentary under Secretary of State for the Department of Health to look at continence services and advise on guidance. This working group concluded that organising continence services in an integrated way that focussed on identifying patients, assessing their condition and putting appropriate treatment in place was essential. *Good Practice in Continence Services* (DoH 2000) was published and highlighted that there were a number of problems across the country that affected access to and delivery of continence services. Recommendations were made for:

- principles for service commissioning
- components of service delivery
- approaches to service organisation
- tools to improve service provision

There have been great improvements in service provision in all of these areas over the last two years and there are many excellent examples of 'Good, better and best practice' towards developing Integrated Continence Services but there is still a long way to go.

Key points for future action

Principles for service commissioning

- Commissioners and continence services should talk to each other
- Continence is an issue relevant to all areas of patient care and as such should be woven into local Health Improvement and Modernisation Plans (HIMP)
- Funding for Integrated Continence Services needs to be identified within each Primary Care Trust service and financial framework (SaFF)
- Local Authority and social services staff should be consulted with and involved in planning Integrated Continence Services (ICS)
- There should be a local continence task force to steer implementation of the guidance

Components of service delivery

- Greater emphasis must be directed towards treatment rather than containment of incontinence
- Users and carers should be identified and consulted about service development and delivery
- On going education for front-line staff in continence promotion, assessment and management is needed

Approaches to service organisation

- More attention to and dissemination of good practice is needed particularly for older people and children and the special target groups, people who have physical or learning disability, prisoners, the homeless and ethnic minority groups
- Services provided by the independent sector should not be overlooked

Tools to improve service provision

- Examples of good practice and resources should be shared so that work is not duplicated
- Information technology (IT) solutions should be available to assist in service delivery
- Standardised assessment tools and care pathways should be more easily available

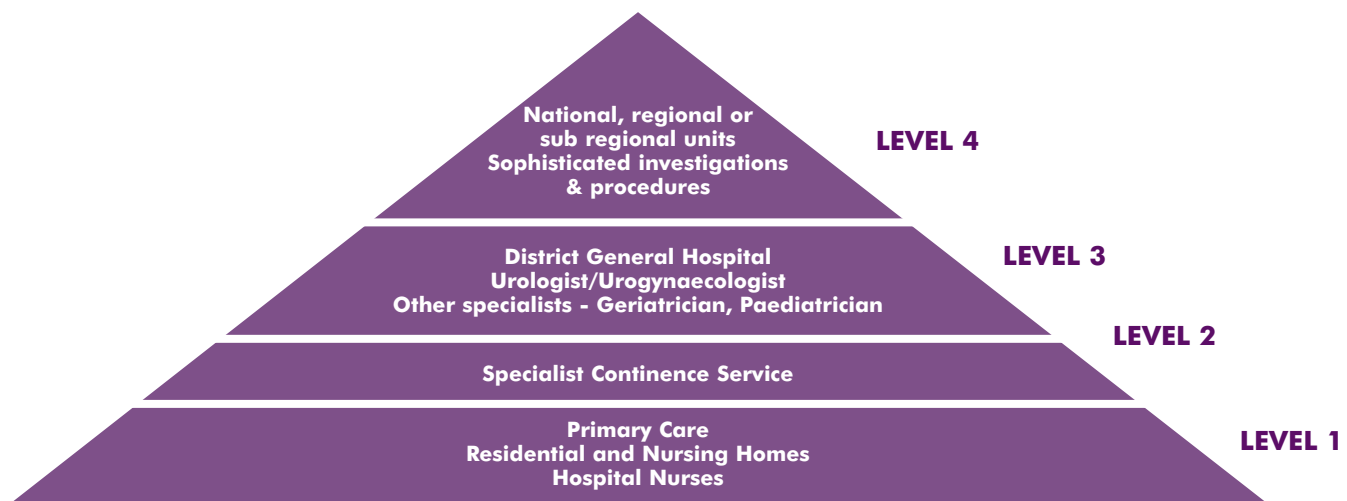


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Introduction

1. *Good Practice in Continence Services* (DOH 2000) was launched over two years ago. This document came as a result of an NHS Review on continence services which identified that continence service provision across the UK was not equitable. To resolve service problems the review recommended a new vision for ICS and placed the onus for commissioning these on Health Authorities and Primary Care Trusts (PCT's).
2. The guidance stated that services should 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. Additionally the document stated services should cover prevention as well as treatment and management of incontinence with the heaviest responsibility for delivering appropriate continence services placed on primary care teams. Specifically a four stage approach to continence service delivery was defined with the service lead the Director of Continence Services.

The Integrated Continence Service



3. The Government expressed strong support for the report recommendations but *Good Practice* was launched at a time of enormous organisational change in the NHS when new commissioning structures are forming through organisational mergers and PCTs leading on delivery of the NHS Plan and associated National Service Frameworks (NSFs). It is therefore not surprising that this reorganisation has led to a degree of management paralysis with other national priority areas like waiting list reductions taking centre stage.
4. The NSF for Older People (DOH 2001) incorporated the Governments vision to achieve ICS and stated that plans for the development of these services should be included in each PCT HIMP by 2003 with full integration of continence services taking place by 2004.

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5. Progress has been made and some areas are developing shadow ICS in conjunction with PCTs and NHS Trusts. New partnerships are developing between services not previously involved in continence care and there is a wider recognition of the need to integrate and benchmark continence services as a result of the NSF and the *Essence of Care* (DoH 2001) standards.
6. Progress should continue with these directives and additionally with the National Institute of Clinical Excellence (NICE) scope for a national audit of urinary and faecal incontinence in older people, scheduled for publication in 2003.
7. In the 12 months between July 2001 and 2002 the Continence Foundation and Royal College of Nursing (RCN) undertook a survey to gain a clearer picture of continence service commissioning and provision across England. The survey was to develop a baseline measure of 'where we are now' in terms of the development of ICS. The questions asked in the survey were based on the criteria set out for service development in '*Good Practice in Continence Services*'.
8. It is accepted that not all areas providing continence services may yet be in a position to develop an ICS in fact the problems encountered in gaining this information reflect the fragmented state of some services. However the aim of the survey was to encourage those involved in the management of people with incontinence to work towards providing the best possible services. This is often achievable within existing budgets and requires only extra application and dedication on behalf of the service provider. The main findings are summarised in this briefing.

Overall assessment of progress

Principles for service commissioning

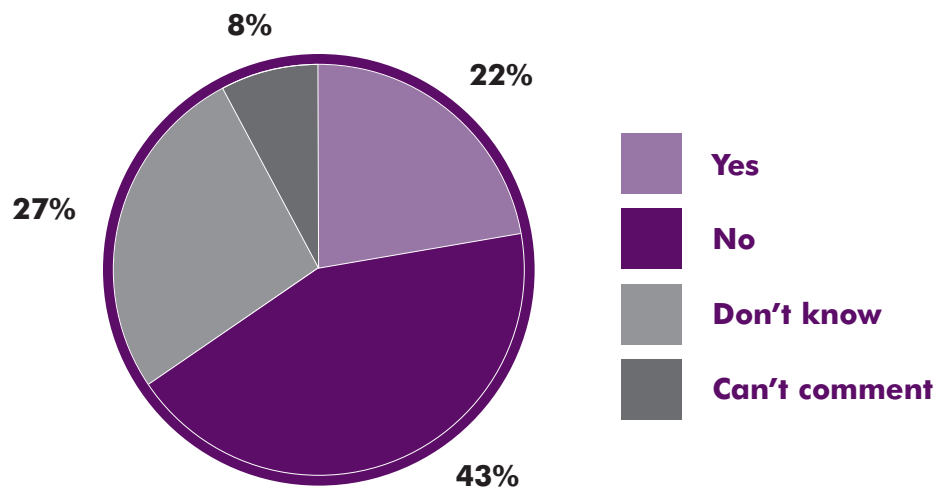
9. This survey has revealed a national network of highly qualified continence advisers and interested clinicians who wish to develop the currently inequitable continence services in England into first rate comprehensive services for all. Some PCTs have made a concerted effort to review and develop services but action is still needed at both a national and local level in order to improve continence management in the UK. Overall organisation of the programme of work to develop local integrated continence services has generally been led by key stakeholders in continence service delivery. These tend to have developed from continence service professionals i.e. urologist, gynaecologist and continence advisers with basic arrangements for implementation built on a local continence task force. The main aim of the guidance, to develop an ICS, is still in its infancy in many areas. The key driver for change will be partnerships between current continence services, PCTs, Local Authorities, Social Service Departments and users and carers. Without these partnerships it will not be possible to achieve ICS. Communication between services is key.

Primary care awareness of the guidance

10. Overall 64% of PCTs said they had a copy of 'Good practice in continence services' and an additional 6% had read it or seen it on the DOH web site. Almost a third of respondents however did not have a copy or were unable to comment on this question.
11. Incontinence is a common and serious problem that significantly affects the quality of life of individuals of all ages. In older people, urinary incontinence can mean the difference between living independently at home and admission to long term care where up to 80% of residents are likely to be incontinent (DOH 2001). Incontinence is costly; estimates reveal a total cost to the country of £2 billion by 2020 (Roy 1997). It is clear that the Government is aware of the significance of both urinary and faecal incontinence but this significance is not yet fully appreciated in primary care.

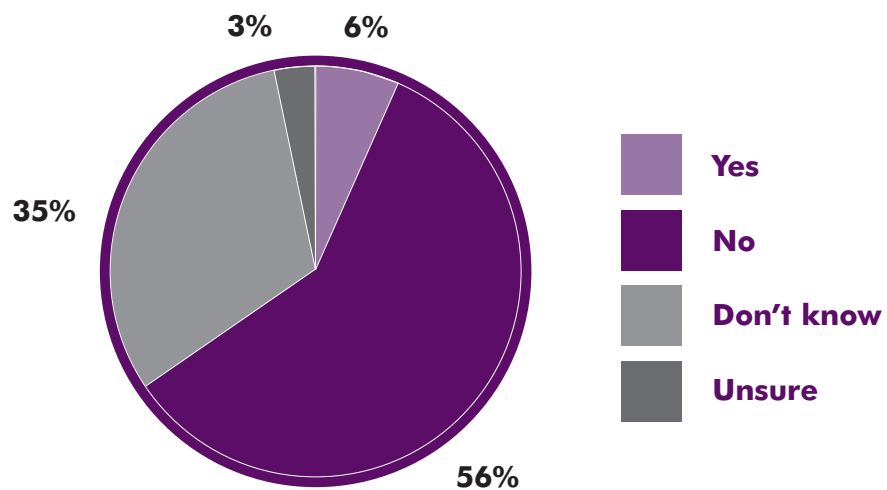
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12. Although 56% of the organisations surveyed said they had plans to develop an ICS only 22% had discussed this development at PCT Board level. The remainder had not discussed this (43%), did not know if it had been discussed (27%) or could not comment (8%). Much more needs to be done to engage PCTs in continence service development and greater efforts are required to develop relationships between specialist continence teams and PCTs. Particularly more needs to be done to increase the strategic contribution of continence advisers at PCT board level to assist commissioning. Continence advisers said they felt excluded from decision making and felt they lacked influence at PCT board level. How continence services could open an effective dialogue with PCTs was a frequently asked question.



Director of Continence Services

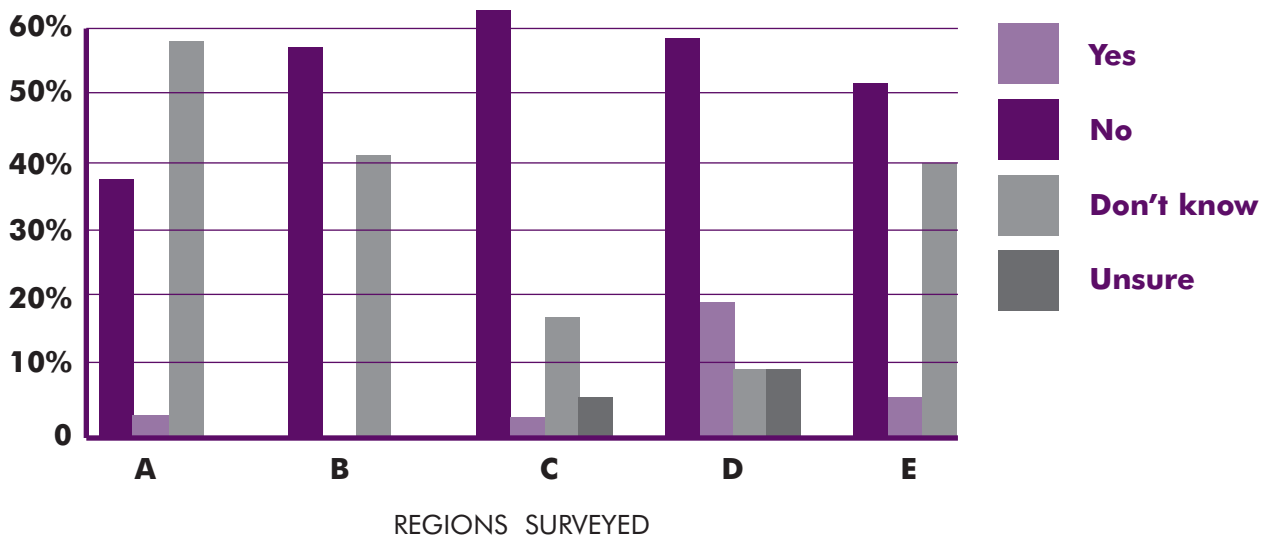
13. The Director of continence services is seen by the DoH as the central element in moving the ICS forward but only 6% of those surveyed intended to appoint a Director of Continence Services. Over half (56%) said they had no plans to appoint a Director and over a third did not know.



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14. 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 and gynaecologists. It will also require contributions from other specialists; coloproctologists, geriatricians and paediatricians, midwives, occupational therapists and the involvement of primary care teams; GPs, district nurses, practice nurses, health visitors and school nurses. Other team members will include social services, nursing and residential home carers, the voluntary sector, patients and carers.
15. Such a disparate team requires a senior team leader or Director who is capable of team building, of promoting the continence service at both a Trust board and Strategic Health Authority (StHA) level, and of 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 PCTs and the leader would need to have access to the PCT board.
16. The main problems cited for non-appointment of a Continence Director was the name and funding. Only one area in the survey indicated that they did not have a problem with the title 'Director'. The remainder all stated that Director implied that this was an executive role and their PCTs felt that if they were to appoint a Director for one service they would be pressurised to appoint Directors in other areas. Director salary also needed to be identified. At the time of interview two areas who had been successful in their bid for funding in the SaFF for a 'continence lead', had their funding reduced because of competing pressures, making it necessary to develop alternative solutions for the post.

Regional comparison of Director development

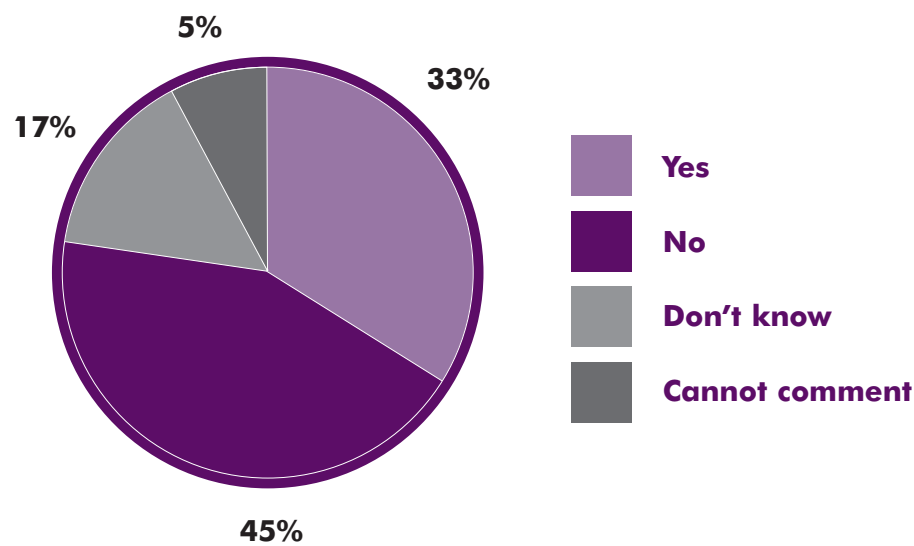


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Government Health Plans and the HIMP

17. The HIMP in each PCT needs to address key targets within the NHS Plan, the Cancer Plan and the National Service Frameworks. Although continence is not a specific priority of the NHS Plan it is relevant to each of several priority areas and a requirement of the NSF for older people. Poorly managed incontinence often leads to inappropriate hospital or long term care admission, delayed discharge and blocked hospital beds. Capacity planning across the healthcare community is an important aspect of health service management and one in which continence management plays a role through preventing inappropriate hospital admission.

18. Only one third of those surveyed said that continence was mentioned on their HIMP.



Components of service delivery

19. *Good Practice* in Continence Services is aiding many positive developments in the delivery of continence services. Several areas have had successful bids to their local HIMP for additional funding for staff to improve continence management in primary care. This has enabled the development of differing service models for continence management for example continence co-ordinators and continence link nurses. The number of continence adviser posts in the UK has also risen from 521 in 2000 to 551 in 2002 but there is still inequity of adviser provision to PCTs particularly for paediatric continence advisers and advisers with an interest in ethnic minority clients.

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20. There has been a greater recognition and wider involvement of the multidisciplinary continence advisory team in the prevention, management and treatment of incontinence as in the Chorley and South Ribble Primary Care Trust (Pomfret 2001, Vickerman 2001)
21. The NSF for Older people without doubt has been a useful lever for stimulating a review of many continence services. Other developing NSF's (diabetes, children, and long term conditions) will build on this. Benchmarking services using *Essence of Care* has also increased the focus on continence services.

Health and Local Authorities: Residential and Nursing Homes

22. Other recent policy has given a negative focus. From October 2001 the Government, responding to the Royal Commission on Long Term Care, implemented changes in funding nursing 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). Additionally Government stated that all nursing home residents would be eligible for free continence products. Self-funders were to be assessed for these from October 2001.
23. The launch of the 'free pads' for nursing homes directive has brought containment back as a main issue in continence care for nursing homes reducing the opportunity to promote continence and enable an assessment led continence service. This directive has made many commissioners see containment products as the only management option available for people with incontinence.
24. The current lack of care home beds and the pressure on hospitals to discharge patients into the community has also placed pressure on care homes to accept more dependent residents who may well be incontinent. In many cases, staff are not trained to provide the appropriate nursing care that such patients require. The single assessment process (SAP) should help to overcome this problem, although this can only be effective if assessors are trained adequately and if they are able to act on the results of the assessment. There is currently no national standard for the assessment of continence but such an assessment should be triggered by questions in the SAP. As the SAP will be monitored by StHAs, PCTs will be required to assess continence effectively and this in theory could help improve the continence management of older people.
25. A survey of 38 care homes in the Midlands highlighted deficiencies in continence care provided by staff. In the homes 75% of residents were incontinent and the cost of disposable continence pads was almost £250,000 per year. Severity of the incontinence was not however recorded or monitored and there was no record of the rationale behind why mostly pads were chosen as the management option or why other options had not been tried (Blannin 2002).

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Health and Local Authorities: children

26. Incontinence is a problem that can affect almost any age group. In the primary care survey questions relating to the joint targets for children - exclusion of children from school due to incontinence were met by some hesitation and uncertainty. Models of practice for service development may be beneficial in promoting this service area. Doncaster has a nurse led enuresis clinic established in 1995. School nurses offer advice and support to children between the ages of four and seven and as the child approaches their seventh birthday a referral can be made to the enuresis nurse specialists.

Involving users and carers

27. The general principles of *Good Practice in Continence Services* states "ensure users and carers are involved in the planning, provision and audit of services". In general this is not as yet happening and 69% stated that there was not yet consultation with service users although ways in which this could be organised were under consideration. 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, an Asian women's group, an older people / physical disability group and a younger person's physical disability group. These have all been developed using a project worker who speaks Urdu and Punjabi. Links have also been made by the project worker with the local MS Society and Carers Association. *InContact* was also cited as a useful resource for facilitating the involvement of users at a local level.

Education and training

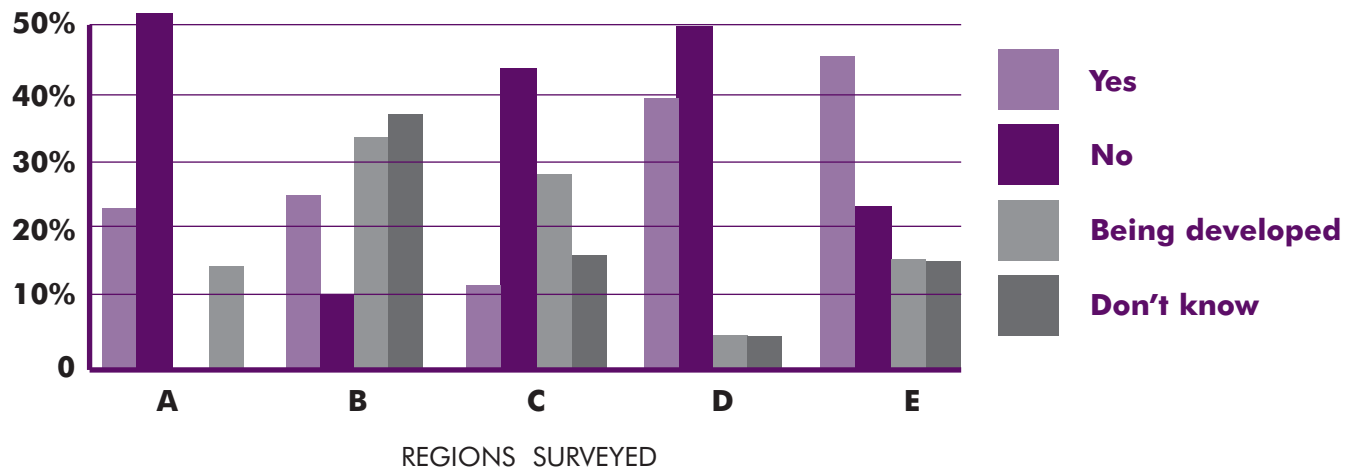
28. Education and training in continence care encompasses a wider range of people and a wide variety of educational and training needs. Throughout the interviews all continence advisers were aware of the need for ongoing education for front line staff in continence promotion, assessment and management.

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Tools to improve service provision

29. Care pathways are a vital component of efficient continence services. There are many useful examples already available which can be locally adapted for each service. Many areas have produced standardised referral / advice and treatment pathways but these need to be more easily accessible, perhaps via the World Wide Web. Although care pathways have been agreed in many areas those developed tended to be between urology and gynaecology services. To a lesser extent primary care pathways, like the Stourbridge Care Pathway, have been developed. Very few areas had developed work with social services. The continence service in Nottingham in partnership with City and County Social Services has provided mandatory training for social care staff, partnership assessments, written guidelines and a link worker scheme. Projects like this could be shared and replicated in other areas.

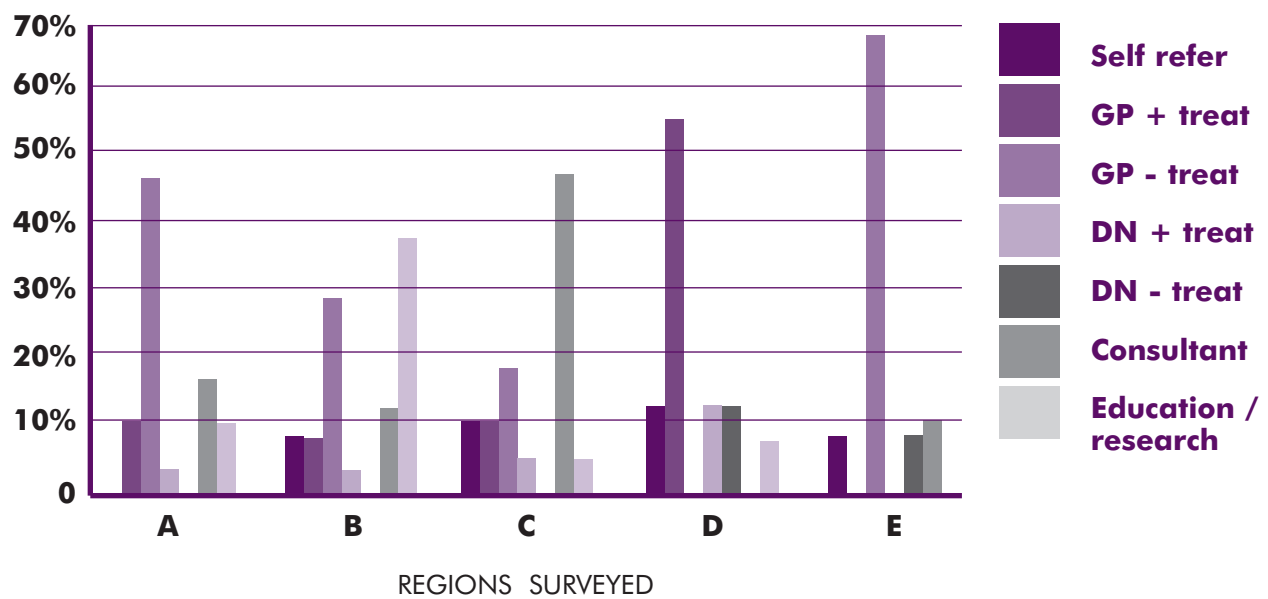
Development of care pathways



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30. Lack of care pathways and treatment guidelines at a local level has implications for secondary care workload. In this survey the most common referral route to continence services overall was from GPs who had not undertaken basic investigations or treatment of patients. This increases pressure on secondary care services and also prevents patients from receiving immediate help to cope with their incontinence contrary to recommendations in *Good Practice* which indicate that primary care should be the first level of care for people with incontinence.

How patients reach continence advisors



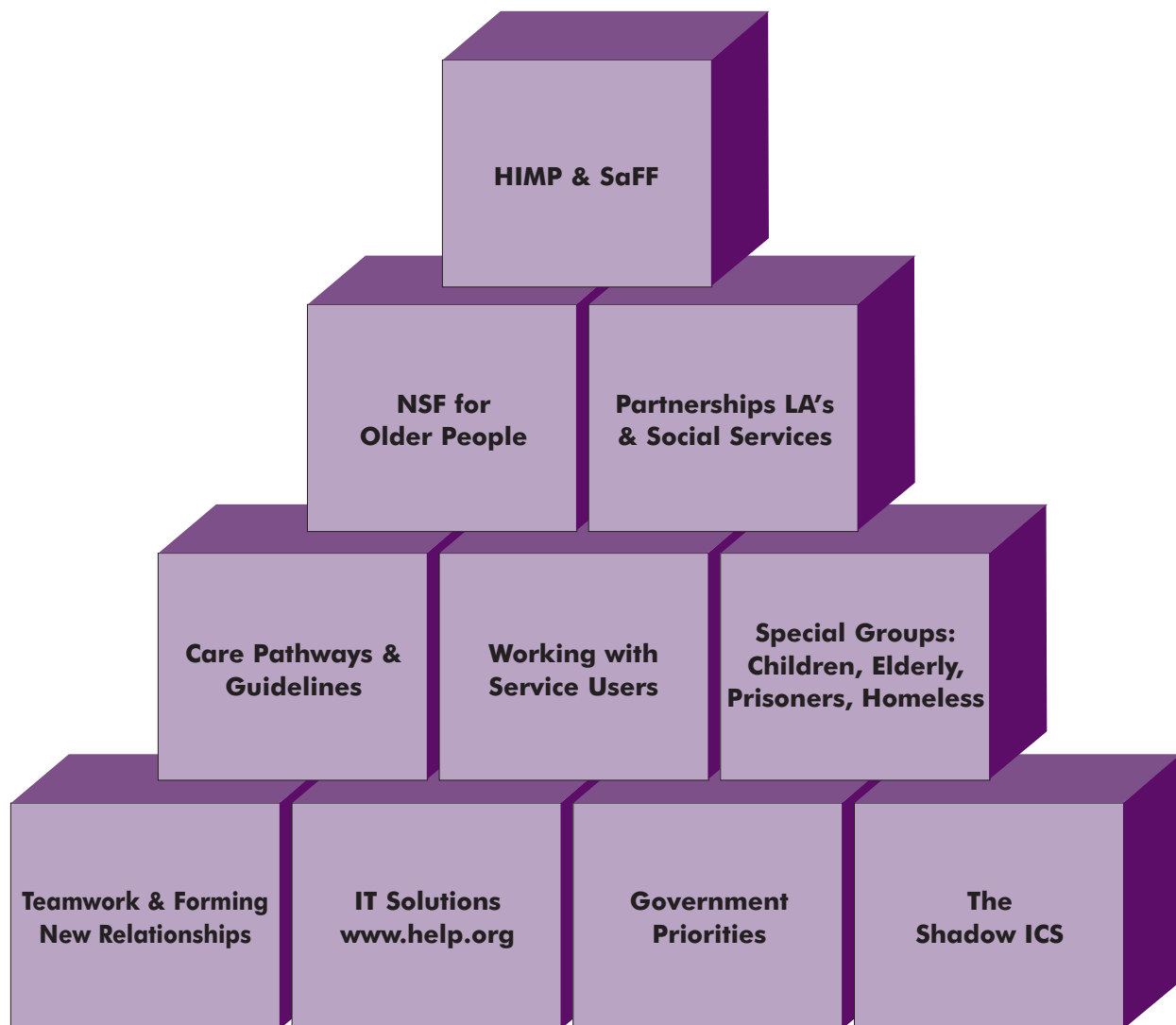
31. In terms of general service delivery a small percentage of continence nurse specialists did not have access to IT systems, computerised data collection systems or clerical support (other than for pad distribution) access to which overall could increase service efficiency.

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Is policy translated into action?

32. Changes are occurring as a result of Good Practice in Continence Services and other policy is continuing the process of change, in particular the National Service Framework for older people, Essence of Care benchmarking standards, the Expert Patient and Modernising Social Services. All should continue to drive the agenda forward. With the fundamental nature of organisational changes now underway 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 PCTs and continence services and that the current networks lobbying for Integrated Continence Services are supported and maintained.

Areas for action



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The Way Forward

33. A local continence task force should be established (if this has not already happened) to identify action to support implementation of ICS. The task force can:

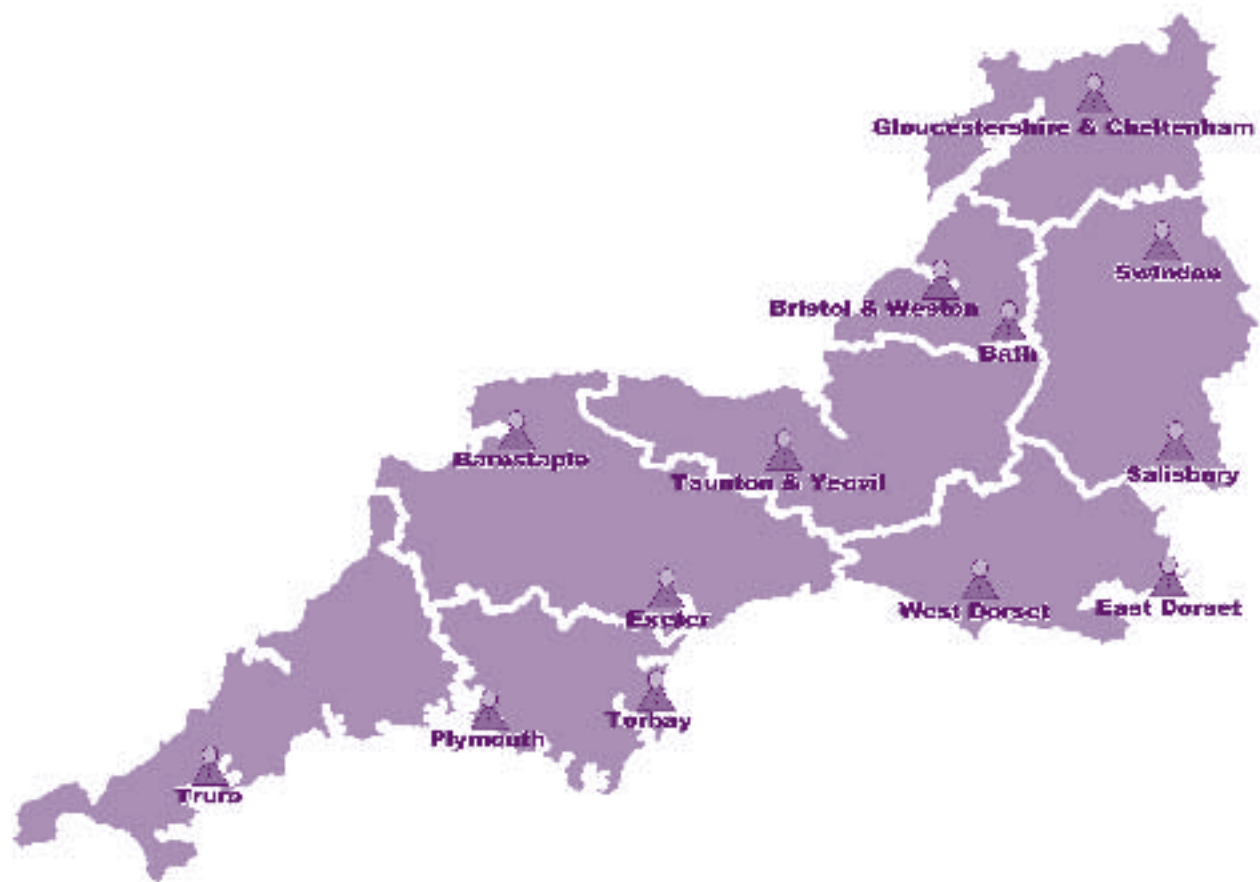
- consider best practice and means of dissemination
- ways of improving performance
- produce advice on activities

Local networks could also be established to:

- share learning
- improve co-ordination
- address development priorities

All areas should be forming 'Shadow Integrated Continence Services' identifying their Director and designated specialists and approaching PCTs with proposals developed to move the continence agenda forward.

Shadow Integrated Continence Services of the South West

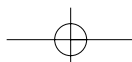
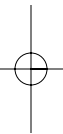
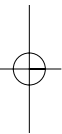
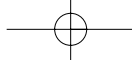


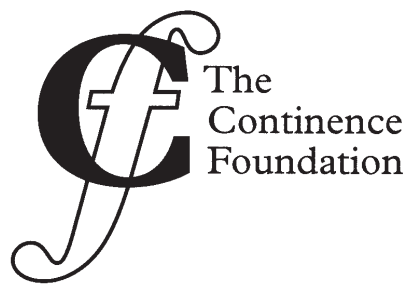
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**If you would like help in
developing your
Integrated Continence Service
the Continence Foundation can assist.**

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