# Chapter 8

## Case management

8.1 Throughout the committee's inquiry many stakeholders labelled Australia's palliative care system as fragmented. One recurring theme in responses to this fragmentation has been that a method of case management be introduced to assist families and carers navigate the system at what is a very stressful time.

8.2 The perceived fragmentation of palliative care is consistent with what this committee is often told about fragmentation and coordination problems with the wider health system. In palliative care it results at least in part from the fact that the provision of palliative care services, although jointly funded by the federal government and the state and territory governments, remains the responsibility of the individual state and territory governments. These governments both have and require the flexibility to allocate those funds to meet the needs of their different population and demographic characteristics, meaning there are varying delivery models and organisations. The service providers are generally those providing aged care services, but the service itself is not aged care. Service provision differs radically between rural and urban settings, and despite the fact that life-limiting illnesses do not discriminate based on age, many palliative care services and settings relate in some way to aged care.

### The fragmented approach to palliative care provision

8.3 Throughout the committee's inquiry it became clear that there is much variation in the standard of care being delivered. In addition to the variation, the committee consistently heard of difficulty being experienced by carers and families as they sought to access palliative care services through the health care system and spoke of its fragmented nature. SARRAH explained their concern that the provision of palliative care and therefore access to palliative care is currently fragmented:

> We are of the view that Australia should be justly proud of its health system, which offers a range of palliative care services. However, these services across the nation are fragmented and not coordinated.[1]

8.4 Catholic Health Australia suggested that the current fragmented nature is the result of the fact that palliative care in Australia is still relatively new:

> In some respects, specialist palliative care is still in its infancy. Services have grown up very much in an ad hoc fashion across Australia. There is no consistency. What does a specialist palliative care service look like? It varies from location to location and from state to state.[2]

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[1] Mr Rod Wellington, Chief Executive Officer, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, p. 29.

[2] Professor Katherine Clark, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 39.

8.5 The Medical Oncology Group of Australia (MOGA) explained that the disparity between service provision in rural and regional areas and services provided in metropolitan areas is concerning:

> …in that area of traditional end-of-life care there is a great lack of conformity around the country in terms of access to specialised palliative care services, and the heart-wrenching comments that have come to us from our members who work in regional and rural Australia really reflect that devastation of the oncologist trying to manage these patients right to the end, often as the only oncologist in town without the back-up of hospice facilities and community nursing and sometimes even access to basic drugs in local pharmacies that you would need for end-of-life care. So that is one problem. In the city, it is not so bad for that traditional pointy end of palliative care, but in the country it is a big problem.[3]

8.6 Professor Jane Phillips suggested that the effectiveness of palliative care service delivery could be improved through a more coordinated and focused approach at the federal level:

> …we need to enhance the delivery of palliative care, strategically, at the Commonwealth level, either through a lead agency or through an enhanced palliative care division. That is really looking at the ways in which the Commonwealth needs to be able to work across operational boundaries, to focus on improving palliative care. If we look at the many reform documents that have been published, palliative care gets a mention in many of them, but it actually requires reform in primary care, aged care, acute care services and community based programs.[4]

8.7 A solution proffered by many witnesses to the current fragmented approach to palliative care was the introduction of a case manager to assist families and carers through what is an extremely difficult period.

## The case management response

8.8 Mrs Fiona Engwirda spoke of the difficulties she encountered when trying to navigate the system to access services and equipment necessary to deliver palliative care to her daughter:

> I am an educated and articulate member of the community and I cannot stress enough how difficult this process has been for me. I am concerned that other members of the community who may be isolated, may not speak English as a first language or may be marginalised with various reasons may be lost in the system when they should be supported. I acknowledge the difference that exists between disability and palliative care but also the

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[3] Association Professor Frances Boyle AM, Former Executive, Medical Oncology Group of Australia, *Committee Hansard*, 2 July 2012, p. 41.

[4] Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, p. 58.

> crossover that is intrinsically linked for many children with complex medical conditions.[5]

8.9 When the views of stakeholders were sought on the idea of a case manager in the palliative care system, there was general support for case management as a key feature in the provision of palliative care given the level of fragmentation and the complexity of navigating the system.

8.10 Dr Jenny Hynson of the Australia and New Zealand Paediatric Palliative Care Reference Group spoke of the pain parents encounter when trying to navigate the system and how this could be assisted through the implementation of a case manager:

> Dr Hynson: She certainly would not be the first parent to make a comment like that. I had a father say to me that there were two nightmares: one was the illness and the fact that my child was dying, while the other was trying to navigate the system. There is layer upon layer—
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> Senator MOORE: And every state is different. There seems to be commonality in the fact that it is tough.
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> Dr Hynson: Yes. I was on the edge of my seat while listening very intently to the occupational therapist, because I am so familiar with the issue of families not being able to get the basic equipment they need and the respite. Parents very willingly take on the task of looking after their child. Home is the centre of care. All they are asking is that they have the information, the support and the infrastructure to do it, and that they can have a bit of a rest from time to time. Most of their requests are very modest. They are not asking for somebody to come and do this. They do not want to be in hospital, which is where they end up because the system is not great.
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> So, case management is a huge piece of it. In our experience it is patchy. If you get a good case manager everything works superbly. If you get a case manager at all, the experience and knowledge is variable.
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> Senator MOORE: Where would you get a case manager from?
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> Dr Hynson: A lot of families with children with conditions like this have packages of care. Some of them are able to—
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> Senator BOYCE: Through disability funding?
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> Dr Hynson: Yes, and a case manager may or may not come with that. If one does come, they may or may not have the expertise to know where to access other support for the family. We have a case manager with my team, and a lot of equivalent teams throughout Australia—
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> Senator MOORE: Based at the children's hospital?
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> Dr Hynson: Based at the children's hospital. So we would make sure families are linked into all the things that we are aware of and our case manager would work with others in the community to pull that all together. But, of course, not every family gets to us, or they get to us late when the clinical staff decide that the child is in a palliative phase. Because it is often

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[5] Mrs Fiona Engwirda, *Committee Hansard*, 2 July 2012, p. 24.

> not acknowledged that that is where it is going, the referrals often do come late, which means families miss out on supports further upstream. I think that trying to put this into the control of families as much as we can would be a great thing, and trying to pull together some sort of one-stop shop that could be internet based is on our list of things to do. I think this is where the reference group could potentially be, because it already exists. I am happy to talk about how we could take it to a better place, but there is already—[6]

8.11 The Australian Nursing Federation informed the committee of their support for case management stating:

> …it is absolutely imperative, particularly when there is distance involved, that there is someone who can really pull that together. I am sure you have heard lots of times about the different agencies involved and what a nightmare it is. Often, again, it is about who is in the community. I know that in some instances it might be the allied health person. It is about who has a good, permanent—and I underline the word 'permanent'—relationship with the individual in the community. We go on about fly-in fly-out, but that is another issue.[7]

8.12 Dr Yvonne McMaster, a retired palliative care physician explained how she considers case management could operate to ensure the provision of adequate palliative care:

> What is needed now is a palliative care project manager in every Medicare Local, to ensure that palliative care has the right priority for the community. There are many things that that project manager could be doing. The rural nurses are overworked and overstretched, and many are approaching retirement age. They are holding on by their fingernails, doing a magnificent job—trying to teach the GPs, having to do battle with them; most have no office back-up and no relief; the conditions are almost Third World.
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> We need more social workers throughout rural New South Wales to ensure that the psychological, social and clinical needs are met. There is a big role for case coordinators, and social workers are filling in some of that, but they need Medicare items for end-of-life and palliative care consultations. That may be something the committee can carry forward.
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> What I am suggesting for rural palliative care is that 11 major towns in New South Wales be strengthened as palliative care hubs. Each should have funding for a palliative care specialist as soon as one can be found. We should be recruiting for palliative care specialists for these towns from the UK and New Zealand. I am told, however, that services are required to have six failed attempts at recruiting within Australia before they are allowed to

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[6] Dr Jenny Hynson, Australia and New Zealand Paediatric Palliative Care Reference Group, *Committee Hansard*, 4 July 2012, p. 27.

[7] Ms Geri Malone, Australian Nursing Federation, *Committee Hansard*, 24 April pp. 42–43.

> recruit overseas. It seems to me a good way to put off having to spend any money. Can you put a stop to this?[8]

8.13 The ACT branch of the Health Consumers' Association of Australia were also complimentary of the suggestion raised of having a case manager to assist carers navigate the system when trying to access palliative care services:

> CHAIR: In the very short time we have got left I would like to ask about one of the issues that came up this morning, that it would be good to have case managers. We had an example of where Ms Jackman was telling us about her experience with her husband and trying to organise care and coordinate the care herself. She has experience in health care and herself did not know where to access particular services. We have subsequently discussed that with a number of witnesses. What are your thoughts? Would that be something useful if a case manager could be identified that can help the consumer access care, identify information and work out what they need when.
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> Ms Snell: Absolutely. I think that that model is incredibly valuable. We have often heard our members talk about having a navigator, which is a similar kind of model, within the hospital system, particularly for the elderly. It just gets beyond their ability to cope. Those people who have got family able to take time off work continually get by, but I think of those who do not have them, who are not that well-resourced. They are lost in the system.
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> Dr Stevens: I do think sometimes that the palliative care nurse practitioners in some ways function in that role.[9]

8.14 National Disability Services explained that case management could be particularly helpful in situations where a patient's needs are complex:

> Case management is appropriate where the person's needs are complex and there are a number of parties that need to work together well. So in many cases that would be appropriate, I think, when a person reached the end stage of their life. The example we gave in our submission in relation to the NPY Women's Council and the way in which they managed to pull together a lot of relevant parties, some of which may not have been otherwise thought of, was, I think, a good indication of how a case management approach is quite important.[10]

## The case manager

8.15 There was widespread support for the idea of a case management approach. The committee considered which professionals were well placed to be case managers,

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[8] Dr Yvonne McMaster, *Committee Hansard*, 24 April 2012, pp. 71–72.

[9] Ms Kerry Snell, Consumer Representative Program Coordinator; Dr Adele Stevens, President, Health Care Consumers Association ACT, *Committee Hansard*, 24 April 2012, p. 49.

[10] Dr Ken Baker, Chief Executive Officer, National Disability Services, *Committee Hansard*, 24 April 2012, p. 68.

and how case management can operate without adding additional layers of bureaucracy or complexity.

8.16 Services for Australian Rural and Remote Allied Health (SARRAH) suggested that although general practitioners (GP) were often suggested, in some rural and remote areas that was not practical and an allied health provider would be more appropriate:

> Mr Wellington: The issue was raised about who should lead that case management team. We have a view that it does not necessarily need to be the GP. In some rural and remote settings there may not be a GP, it may be an allied health professional.
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> Mr Bishop: We have an amazing member from Western Australia who is a dietician who has worked in that community for many years and has a really strong rapport with the Aboriginal people in that community. That person, who has the trust and rapport of those people community, would seem to me to be the most appropriate person to be a case coordinator.
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> Mr Wellington: Another example, just leading on from that, relation to Aboriginal health workers in remote communities, where there are no GPs. Why shouldn't they be deemed as appropriate case coordinators, particularly given that there are a range of cultural issues that need to be acknowledged?[11]

8.17 Alternatively, Palliative Care Australia suggested that the new Medicare Locals be used as a vehicle for delivering better palliative care to the community:

> …we will have dialogue continuing as these Medicare Locals develop and evolve. Because palliative care is not that high profile, if you like, in the healthcare sector, there is a considerable amount of advocacy that needs to be done in this area, through Medicare Locals and through the boards being advised that palliative care is an important issue and that end-of-life care must be considered. It comes down to advising those boards about palliative care, and hopefully the process we are going through now is one measure to do that.
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> …when you talk about palliative care, it is like: 'No, we haven't really thought about that because we have a list of hundreds of other things that we see as priorities locally.' But, when you start to discuss palliative care in the sense that it is a public health issue and that it is an issue that really needs to be taken on board from a primary healthcare perspective, then they start to think, 'Yes, this is something we need to consider.' This comes back to the notion of Medicare Locals and local hospital networks becoming a bit more involved in it…[12]

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[11] Mr Rod Wellington; Mr Michael Bishop, Life Member, Services for Australian Rural and Remote Allied Health, *Committee Hansard*, 24 April 2012, p. 34.

[12] Dr Yvonne Luxford, Chief Executive Officer; Dr Ian White, National Policy and Communications Manager, Palliative Care Australia, *Committee Hansard*, 24 April 2012, p. 20.

8.18 Catholic Health Australia however expressed some reticence at placing too many expectations and responsibilities on Medicare Locals:

> We are in the process of rolling out Medicare Locals that are to be the hubs meant to oversee this coordination of services. I do not want to overburden the Medicare Locals because they have modest operational budgets and [there are] many aspirations for them. It would make sense that the Medicare Locals become the place in which aged-care providers, as the illustration, relate to ensure that there is access to the specialist palliative services within their aged-care facilities. That then triggers the discussion that the aged-care facility is not currently funded via the aged-care funding instrument for a specialist palliative care function. It is one thing to have access through the Medicare Locals to the coordination of it; it then needs to determine that the aged-care funding instrument would need to be expanded to have a specific palliative care capability within it.[13]

8.19 Palliative Care Nurses Australia (PCNA) suggested that GPs may reluctant to take on the workload that would be required of a case manager, and that nurses could effectively fill the role:

> Some nurse practitioners are already working with GPs. They are in the GPs' surgeries seeing people and going out to visit them as well. They can take a lot of the load off the GP for the more run-of-the-mill issues that might arise. If somebody's pain management needs changing but nothing is really new apart from a slight increase in pain, then the nurse practitioner is able to just increase the current medication.[14]

8.20 The PCNA went on to explain how palliative care nurse practitioners would be effective case managers:

> The care of somebody in that situation [community palliative care] is complex, and it can change very quickly. So a big part of the role of the palliative care nurse is being able to anticipate what might happen and talking to the family and saying, 'All right, if your relative deteriorates then these are some of the things we might have to look at—for example, putting the person into respite.' So it is helping the family come to terms with the fact that they may have to do that in the very near future…
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> …communication skills … [are] fundamental to what we do in the area of palliative and end-of-life care. A lot of the problems that arise, particularly in the acute hospital setting, are because many health professionals, particularly medical specialists, are just not comfortable having those conversations about end of life and their communication skills are not necessarily excellent, shall we say.[15]

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[13] Mr Martin Laverty, Catholic Health Australia, *Committee Hansard*, 2 July 2012, p. 36.

[14] Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 61.

[15] Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 62.

8.21 PCNA consider that palliative care nurse practitioners would be a natural fit for the case manager role:

> …Having worked as a clinical palliative care nurse in the community, that is very much part of our role: going out, seeing how the patient and the family are managing and organising extra services for the family. Often they struggle with the amount of care that is required for the person with an end-of-life-stage illness at home… So it is a big ask for families, and as health professionals we recognise that and are very alert to the signs that they need more help.[16]

8.22 Professor Jane Phillips, a Professor of Palliative Nursing at the University of Notre Dame and St Vincent's Sacred Heart, echoed the views of PCNA explaining to the committee that nurse practitioners, in conjunction with Medicare Locals, could ensure effective delivery of palliative care services:

> …nurse practitioners are an exciting and evolving role, but it is a role in which we really want to make sure that nurses are working in partnership with other members of the interdisciplinary team. It is not necessarily about being an independent practitioner. There is great scope to be thinking about nurse practitioners integrated into Medicare Locals.[17]

8.23 In making this point however, Professor Phillips highlighted the importance of ensuring consistency in the nurse practitioner role regardless of location.[18]

8.24 Despite hearing general support for the concept of a national case management system, Mrs Julianne Whyte of Amaranth Foundation expressed some reservations identifying the importance of first establishing how case management would actually work:

> …in a lot of the Hansard reports and a lot of other submissions people talk about a 'case management' approach. I have really struggled in our research to look at what 'case management' meant and what it was. Even when I was working in care respite as a case manager there were issues around whether it was a professional case management or referral brokerage model—how people interpreted their role of case manager. Our research showed that it really needs a very professional social work type approach to a case management model, similar to what they are doing in mental health—recognising that it needs this comprehensive skill set that perhaps is not being provided at the moment.
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> …we found from our research that social work perhaps should be and could be the better profession to deliver a lot of the care coordination or supportive care that is not being provided to people in palliative and end-of-life care. Some of the research that we did, especially with the division of

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[16] Mr John Haberecht, Palliative Care Nurses Australia, *Committee Hansard*, 24 April 2012, p. 61.

[17] Professor Jane Phillips, Professor of Palliative Nursing, University of Notre Dame and St Vincent's Sacred Heart, *Committee Hansard*, 2 July 2012, pp. 60–61

[18] Professor Jane Phillips, *Committee Hansard*, 2 July 2012, pp. 60–61.

> general practice, that looked at how we worked with practice nurses, the linked nurses and the supportive care networks to get GPs to do case conferences, family meetings was a really good project with some fantastic outcomes but probably needs to be seated outside of the GP domain rather than within it, because I think it gets swallowed up by the processes within GP services rather than looking at what are the needs of families and caregivers.[19]

8.25 South Australia Health noted the advantages that could be gained through case management:

> Absolutely. Yes, in an ideal world, a case management model at the diagnosis of a life-limiting illness would actively support people to navigate what is a very frightening and difficult area of health care, often because of all the factors that you have raised, and especially if you have a medical practitioner that does not believe in palliative care for a start, which is actually a difficulty that we encounter at a service level.[20]

8.26 Although supportive of the concept of case management, South Australia Health identified that the key to ensuring access to and delivery of effective palliative care relies on the identification and establishment of appropriate clinical pathways, including diagnosis and referral:

> It is certainly a challenging area. The work that we have looked at through the clinical network is to try and get pathways nailed that are clear and easy to use for the primary care providers specifically. We have a working party at the moment looking at referral criteria into palliative care, because I think that is the first area where it actually falls apart. We went through a stage many decades ago where palliative care accepted every comer, and now the demand has outstripped the resource and we have got specialist teams. So where is specialist palliative care different from general end-of-life care and how do we actually articulate that? The onus is on specialist palliative care services to make clear statements about what the referral criteria are, to make it clear and simple so that it is well understood and then support that with education.[21]

8.27 South Australia Health further explained that they are currently working on establishing and identifying these pathways and hope that it will ensure people do not fall through the gaps:

> We have key clinicians and also the primary healthcare sector, oncology, all our chief referrers sitting around the table nutting out, right down to the language, what is going to make it clear and simple so that they will actually know whether this is a referral that will get into palliative care or whether they need to be going somewhere else. And if they are going somewhere else, palliative care also need to be clear in helping to guide

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[19] Mrs Julianne Whyte, Chief Executive Officer, Amaranth Foundation, *Committee Hansard*, 10 July 2012, p. 28.

[20] Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 23.

[21] Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 23.

> them so that it does not become too hard and the gap opens and people fall through it.
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> The next phase of that work is looking at the patient pathway…We have got to look at that patient journey. That is something that the clinical network has been asked to review and, again, to look at it through the eyes of the consumer and not the eyes of the services. So there have been some directions about moving forward that we hope will start to address some of those concerns about consumers not getting services, or not knowing when to get them or how to get them, or what criteria are required for a referral to go through and be realised…
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> …of course it comes back to whose responsibility it is and whether specialist palliative care should take leadership, at least in being able to say, 'The referral's come through and we're going to coordinate other services to take care of the end-of-life non-specialist population.' That is going to need a lot of work to nut that out…[22]

## Committee comment

8.28 Throughout the course of its inquiry the committee has received much evidence suggesting that many people requiring palliative care are unable to access that care given the complexities of the health care system and its fragmented nature. The committee is concerned that the fragmentation of the palliative care system acts as yet another barrier at a time when families are most at need of the support that can be gained through the provision of palliative care services.

8.29 The committee considers that the role of case managers is important. It acknowledges the point made by Amaranth Foundation, that there are different case management models, and there needs to be clarity around what works best in palliative care.

8.30 Case management requires both a person to take on the role, and the allocation of responsibilities to that person. Patients and carers also need to be able to identify who the person is, and where they should go to obtain case management services. All of these things indicate that program funding of some sort would be required: if there is no recognition of the role and no money to pay for it, then it is unlikely to be done, and certainly unlikely to be done consistently, reliably or equitably.

8.31 For this reason a case management model will need recognition at a federal level with the agreement of all of the states and territories. As well as ensuring both funding and consistency, agreement is desirable to ensure that the implementation of such a model did not result in an additional layer of bureaucracy.

8.32 The committee acknowledges the work being undertaken in South Australia to map the palliative pathway in order to understand where general 'end-of-life-care' and specialist palliative care intersect and ensure that the health care providers, whether

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[22] Ms Kate Swetenham, SA Health, *Committee Hansard*, 5 July 2012, p. 23.

they be aged care, primary care or palliative care specialists deliver a consistent and complete standard of palliative care for the patient's palliative journey.

**Recommendation 12**

**8.33 The committee recommends that the Council of Australian Governments consider developing and implementing a case management model.**

**Recommendation 13**

**8.34 The committee recommends that the Council of Australian Governments develop and implement a uniform national palliative care pathway that clarifies when general palliative care moves into specialist palliative care, and maps the diagnosis and referral process to ensure that a palliative patient's journey involves coordinated access to all necessary services.**

**Recommendation 14**

**8.35 The committee recommends that the Council of Australian Governments review the Medicare Locals structure to consider how the provision of palliative care services, both general and specialist, is integrated into primary health care at the local level.**