Building partnerships

A workbook for implementing best practice palliative care for Aboriginal and Torres Strait Islander people in NSW



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Introduction

Building Partnerships has been developed as a practical tool to support the implementation in NSW of the national Resource Kit for providing culturally appropriate palliative care to Indigenous people. The Resource Kit was developed for the Australian Government Department of Health and Ageing as part of its National Palliative Care Program by Wodonga Institute of TAFE, Mungabareena Aboriginal Corporation and Mercy Health Service Albury (Palliative Care).

This Workbook is based on the three Practice Principles identified in the Resource Kit. The Principles assist palliative care providers to meet the cultural needs of Aboriginal and Torres Strait Islanders, their families and communities.

The Practice Principles are:

1 Include Indigenous Australian organisations and/or personnel in the planning, provision and monitoring of palliative care to ensure culturally relevant requirements are addressed and preferences of the patient and/or their family are considered.

2 Communicate with the patient and their family and community in a sensitive way that values cultural differences.

3 Provide training to all personnel to enable the provision of culturally appropriate palliative care to Indigenous Australians.

The aim of Building Partnerships is twofold. Firstly, as the name suggests, it provides a means for Aboriginal Health Workers and Palliative Care providers in NSW to work together to identify local issues for Aboriginal and Torres Strait Islanders receiving palliative care. Aboriginal Health Workers are the key link between Palliative Care Services and Aboriginal and Torres Strait Islander communities.

Developing and sustaining a working relationship with the local Aboriginal Health Worker is vital to providing a co-ordinated approach. Based on mutual trust and respect, palliative care providers can learn the skills, especially communication skills, necessary to provide culturally safe care. Aboriginal Health Workers can also be confident in encouraging Aboriginal and Torres Strait Islander patients to accept palliative care. This cannot happen in one session but will need to develop over time as the different sections of the workbook are explored and discussed.

Secondly, this Workbook will be used as a training manual to assist palliative care personnel provide culturally safe palliative care. It includes research material, general issues identified in the Resource Kit, strategies that have worked elsewhere, and space to note local issues and initiatives for providing care to the local Aboriginal and Torres Strait Islander communities.

This Workbook is an adjunct to the Resource Kit. Palliative care providers in NSW are encouraged to refer frequently to the Resource Kit with its rich stories and detailed background. By incorporating into practice the broader themes in the Resource Kit, the local themes in the Building Partnerships Workbook and the expressed individual patient's preferences, palliative care providers can be confident that they are providing culturally safe care to their Aboriginal and Torres Strait Islander patients, families and communities.

KATE STIRLING
NSW Project Officer

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The project was managed by the Collaborative Health Education Research Centre, St Vincent's Hospital, Lismore.

NSW HEALTH

THE NATIONAL PALLIATIVE CARE PROGRAM

St.Vincent's Hospital
LISMORE, Northern NSW, AUSTRALIA

WODONGA TAFE of Course

Local services for Aboriginal and Torres Strait Islander palliative care patients

SERVICE	CONTACT DETAILS	PHONE
Palliative care service		
Aboriginal health workers		
Community nurses		
Aboriginal medical service/health centre		
Aboriginal community organisations		
Home and community care services		
Emergency housing		
Community transport		
Indigenous ministers of religion		
Household goods		
Meals on wheels		
Equipment		
Travel assistance		
Funeral assistance		
Bereavement support		
Community support agencies, eg St Vincent de Paul		

SERVICE	CONTACT DETAILS	PHONE
Mental health support agencies		
Centrelink		



Contents

9 Improving access

15 Improving communicaton

21 Providing culturally appropriate palliative care

27 Improving the planning and delivery of palliative care to Aboriginal and Torres Strait Islander people in NSW

33 References

35 Bibliography



Improving access

This section of the Workbook provides examples from research on the factors that influence Aboriginal and Torres Strait Islander people approaching palliative care providers sufficiently early in an illness and during the illness to enable appropriate care to be given.

Improving access also provides some starting points for discussion of strategies and activities that will enhance access to your local service provision. The starting points in bold lettering are from the *Resource Kit: providing culturally appropriate palliative care to Indigenous Australians*. Please refer to the Kit for more information. Icons (butterfly and flower) are used to indicate personal and organisational starting points. Writing space is provided on the following pages for jotting down ideas about how you and your organisation can improve access by the local Aboriginal and Torres Strait Islander community to palliative care services. You can use your ideas and comments to develop strategies and activities that are specific to your local population and improve the wellbeing of people who live in your area.

Consider the Workbook as a living document. The ideas you develop today will probably evolve over time, so revisit your jottings on a regular basis. You may wish to make discussing ideas for improving access part of regular staff meetings.

Access: What does the research show?

A major issue affecting the access of Aboriginal and Torres Strait Islander people to palliative care services is the failure of medical practitioners, both in the mainstream and Aboriginal health care systems to refer Indigenous clients to palliative care.[1]

Many Aboriginal people don't go anywhere for help until it is really necessary – when they are desperate and then they will turn up at a local GP.[2]

Palliative care service providers and a number of AMS doctors believe that late diagnosis of terminal illness is one of the major factors in the lack of access to home-based palliative care. [3]

The issue of reluctance to use mainstream services among many terminally ill Kooris was raised as a general concern.[4]

"Aboriginal people won't ask for services."

"We value someone who will take the time to have a yarn."

"We might want to talk to someone from outside the community."[5]

Adequate access to transport for medical appointments, treatments at larger hospitals and collection of medications was a constant difficulty faced by most participants.[6]

Confusion about the role of the AMS and how best to access their services was also raised by most of the participants as an access issue.[7]

'They [Aboriginal health workers] understand your needs and wants … it's good to have your own colour about you in time of need.'[8]

Need for the extended family to pay their respects. Hospital staff need to be educated and made aware about the importance of this expression of kinship for Kooris. Visits by large groups need to be managed in a culturally sensitive manner taking into account the needs of the terminally ill patient, the family and other patients who may be affected.[33]

What are some starting points?



Establish communication processes with specialist centres and local health and community support services to support continuity of palliative care.[15]



Ensure that appropriate third party services are available.[16]



The existence of palliative care service and advice lines should be marketed to GPs and AMS doctors.[17]



Take time to build relationships with the patient and family.[18]



Investigate ways to improve access to palliative care services by Aboriginal and Torres Strait Islander people.



Build a directory of contacts for services relevant to visiting patients and families.



Build relationships between palliative care providers and Aboriginal and Torres Strait Islander community organisations to reduce barriers to accessing services.

Ideas, comments, strategies, activities ...

Access: What does the research show?

The issue of families travelling to cities or provincial centres to visit terminally ill Kooris was raised with reference to their accommodation and support during their visit. Participants highlighted the need for a directory of hostels/accommodation/support services for family members coming to visit the terminally ill in cities/provincial centres.[10]

In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes.[11]

Relocation of Aboriginal patients from their home town to metropolitan hospitals emerged as an issue in almost every interview. While a few participants had a positive experience and received 'good support' and were 'allowed day leave passes, walks in the grounds and phone calls', the majority found the relocation to be frightening, isolating and overwhelming.[12]

Kooris don't have the phone on and so the 24 hours service is not much help. Kooris will wait till Monday and go to the medical service.[13]

Travel to a hospice, nursing home or aged care facility can also be a significant practical problem for families, and families may feel a loss of control if their family member is in a nursing home or aged care facility. People in nursing homes and similar places often feel isolated from their family and culture.[14]

Overwhelmingly, Indigenous people said that the only effective way to spread information about palliative care was by 'word of mouth'. They also suggest that such strategies should be backed up by written information (preferably with an Indigenous cover design or logo) which would usually only be required once people were aware that they had a need.[21]

Late referrals are due not only to underlying health conditions of Indigenous people but also to assumptions of doctors (GPs, AMS doctors and specialists) about whether Aboriginal and Torres Strait Islander clients will want to be referred to palliative care services.[21]

What are some starting points?



Service providers should budget for the employment or brokering in of Aboriginal and/or Torres Strait Islander cultural specialists who could be on call to provide advice.[19]



In one centre on the south coast of New South Wales, the ALO from the district hospital organised a familiarisation tour for an elders group to the newly opened hospice on another (former hospital) campus.[20]



Service providers should keep in mind that Aboriginal and Torres Strait Islander clients may not have telephone access and should either advocate for phone access on their behalf or set up emergency procedures that do not rely on phones.[23]



Participate in Aboriginal and Torres Strait Islander health promotional activities.



Develop strategies for assisting patients and their families become more comfortable in unfamiliar hospital surroundings.



Liaise with local Aboriginal and Torres Strait Islander communities to determine effective ways to disseminate information about the palliative care service.



Listen to the patient's needs and preferences in relation to cultural aspects of their care. This includes their choice of support person, involvement of Indigenous Australian personnel, and spiritual support needs.[67]

Ideas, comments, strategies, activities ...

Ideas, comments, strategies, activities ...



Improving communication

This section of the Workbook provides examples from research on communication processes that influence Aboriginal and Torres Strait Islander people accessing palliative care.

Improving communication also provides some starting points for discussion of strategies and activities that will enhance communication with your local Aboriginal and Torres Strait Islander people about the palliative care service available to them. The starting points in bold lettering are from the *Resource Kit: providing culturally appropriate palliative care to Indigenous Australians*. Please refer to the Kit for more information. Icons (butterfly and flower) are used to indicate personal and organisational starting points. Writing space is provided on the following pages for jotting down ideas. You can use your ideas and comments to develop strategies and activities that are specific to your local population and improve the wellbeing of people who live in your area.

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Communication: What does the research show?

Aboriginal clients are reluctant to use the palliative care service because there is no Aboriginal face in the palliative care service. Someone [an Aboriginal person] needs to walk them through the service and they need to meet the community nurse first – before they will say yes. I often get the Aboriginal Homecare service in instead of the palliative care.[24]

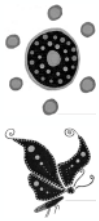
Many Aboriginal and Torres Strait Islander people are unlikely to take up a referral to palliative care unless they receive culturally appropriate support at the time of referral.[25]

There was a strong belief among people we spoke with that palliative care services would cost money (which is often not the case). For many Aboriginal and/or Torres Strait Islander people, a 'normal' visit to the doctor is avoided because of the expense, so there is concern that home visits or nursing would involve costs that families cannot afford.[26]

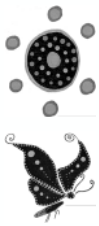
There were reports that people had not been told the true nature or their condition, or were not told in a way that enabled them to understand the implications and what it would mean.[27]



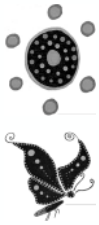
What are some starting points?



Ensure the presence of a community or family member, or an Aboriginal Health Worker to check that the client/s has heard and understood the news about the sick family member, understood the implications and the likely course of the disease and know what sort of services are available.[31]



Partner with Indigenous Australian personnel, organisations and the local community in all levels of planning, service provision, communication processes, and in the monitoring of palliative care for Indigenous Australians and/or their families.[32]



Seeking advice from Elders/ Indigenous Australian community leaders and/or Indigenous Australian health/community organisations on what they see as issues in providing culturally sensitive palliative care.[32]



Include participation by Aboriginal and Torres Strait Islander staff in developing procedures.[32]



Develop and promote policies and procedures to ensure cultural safety. This includes obtaining cultural advice, accessing support services, obtaining consent and adapting care provision models.[33]



Utilise Aboriginal Health Workers, Elders and community members as cultural advocates.[33]

Ideas, comments, strategies, activities ...

Communication: What does the research show?

Even if people were aware of what services were available they would be unlikely to ask. It was suggested that if people were absolutely convinced it was their right and they would not be refused then they might ask for these services.[28]

If referrals are made, but are not supported by cultural advocacy, and/or the participation of Aboriginal and Torres Strait Islander staff, then they may not be taken up.[29]

The desire for terminally ill Kooris to die at home must be acknowledged, understood, and wherever possible, supported. Kooris have a spiritual connection to their homeland and have a fear of dying in hospital. There needs to be consultation with the patient on preference of 'where to die'.[30]

Grief and counselling services had not been accessed by the participants in the study as they were serviced by non-Aboriginal people who 'don't understand Aboriginal ways of mourning.' Some participants also felt they would be unable to 'trust' a non-Aboriginal service and feared 'breach of confidentiality.'[9]

The way in which 'bad news' is delivered is critical to Indigenous peoples' access to palliative care services. People need to be told in a way that is appropriate to their culture and in a way that will support them in making informed choices about their future options. What is appropriate will vary from place to place.[41]



What are some starting points?



Develop literature and audiovisual material about the later stages of life and loss and grief.[34]



Provide information in plain English and in different styles (for example, posters, artwork, diagrams, articles in Aboriginal and Torres Strait Islander publications, radio and television) about palliative care services.[35]



Develop locally appropriate policies and procedures in relation to gaining consent, disclosure and confidentiality.[36]



Confirm with the patient and family that care and treatment information has been understood. Seek advice from Aboriginal and Torres Strait Islander personnel/support person where required.[37]



Seek advice from Aboriginal and Torres Strait Islander personnel, Elders or community leaders on grief and loss issues, and strategies for supporting the patient's family and community in their bereavement.[38]

Ideas, comments, strategies, activities ...

Ideas, comments, strategies, activities ...



Providing culturally appropriate palliative care

This section of the Workbook provides examples from research about the provision of culturally appropriate palliative care to Aboriginal and Torres Strait Islander people.

Providing culturally appropriate palliative care has some starting points for discussion of strategies and activities that will enhance the provision of culturally appropriate palliative care to your local Aboriginal and Torres Strait Islander people. The starting points in bold lettering are from the *Resource Kit: providing culturally appropriate palliative care to Indigenous Australians*. Please refer to the Kit for more information. Icons (butterfly and flower) are used to indicate personal and organisational starting points. Writing space is provided on the following pages for jotting down ideas. You can use your ideas and comments to develop strategies and activities that are specific to your local population and improve the wellbeing of people who live in your area.

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Culturally appropriate care: What does the research show?

Few mainstream palliative care services employ Indigenous people. When asked about barriers to accessing palliative care services, most Aboriginal people's first response was the lack of Aboriginal and Torres Strait Islander staff.[39]

Some service providers are afraid to visit Aboriginal homes.[40]

An Aboriginal Homecare coordinator in New South Wales reported that it had taken several years before the AMS and other service providers started making referrals to her service.

"We [the service] had to build up our profile and had to do door-knocking to get clients for the first couple of years – despite the fact that we have Koori workers. It takes time and energy to build up trust."[43]

High staff turnover, especially in regional hospitals so that few nurses have had cultural awareness training. In remote areas, the use of agency staff and foreign nurses on temporary work visas adds to the problem.[44]

Patients' rooms are too small for visiting family and community members. Aboriginal and Torres Strait Islander community members' experience is of always having to stand in corridors.[45]

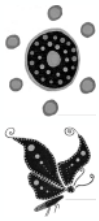
A major issue for Aboriginal and Torres Strait Islander people working in the health system (and in palliative care in particular) is that when a member of the Aboriginal or Torres Strait Islander community dies, they are not only a health professional associated with the event but also (usually) one of the bereaved. Whether as a member of the same extended family or as a member of the local community, they will have been in some way related to the deceased person.[46]

Recruitment of Aboriginal and Torres Strait Islander people into volunteer programs is needed.[47]

What are some starting points?



Employment of trained Indigenous staff or the brokering in of Aboriginal and Torres Strait Islander services is essential.[54]



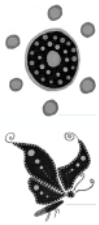
Involve Aboriginal Liaison Officers with palliative care units, either in the hospital or in the community, and in discharge planning for palliative care clients.[55]



Ensure that cultural awareness training takes place (including information about Aboriginal and Torres Strait Islander service providers), to equip service providers with the skills to build relationships with these groups so that they can work together to provide the best support to Aboriginal and Torres Strait Islander clients.[56]



Develop and promote roles to improve existing services; and more hands-on or face to face roles dealing with cultural and/or medical advocacy.[57]



Identify and approach local Indigenous Australian organisations for advice. For example, seek advice about consulting Elders or community leaders on cultural requirements for care.[58]



Incorporate cultural safety training focused on Indigenous Australian needs into professional development for all staff. This includes induction/ orientation for new staff and professional development policies and procedures.[59]

Ideas, comments, strategies, activities ...

Culturally appropriate care: What does the research show?

The need for trained Aboriginal and Torres Strait Islander staff to work in palliative care was repeated again and again by community members and AMS staff.[48]

According to Hunter (1993) non-Aboriginal health workers are vulnerable to causing an offence or 'possibly trouble' if poorly educated on local customs or traditional mourning.[49]

In contrast to community nurses, staff in hospital settings were criticised by many of the participants. They spoke of their experiences of 'racism' in hospitals, the 'negative attitude' displayed to them, and their perception that hospital staff viewed Aboriginal people 'as second in line to white people'. Instances of 'discrimination' ranged from being spoken to in an 'unfriendly manner', 'being spoken down to by white workers', 'poor body language' and 'refusal of treatment'.[50]

GPs also need to be educated on how to communicate effectively with terminally ill Kooris and to explain their disease and treatment/care options appropriately so that the patient understands the situation.[51]

The need for Aboriginal palliative care volunteers was raised. It was suggested that more Aboriginal people could be encouraged to consider being volunteers to help service terminally ill Kooris.[52]

Racism … needs to be addressed with individual practitioners in a safe training and support environment, and confronted at an institutional level where it impacts on policy and practice. A culturally safe palliative practice cannot be developed and sustained unless this work is done.[42]

When asked to specify three cultural groups for which they felt the least competent when providing palliative care 74% of respondents (palliative care professionals) reported Asians of various cultural backgrounds such as Chinese, Vietnamese and Japanese; 45% reported Europeans of various cultural backgrounds such as Italian, Greek and Polish; 19% reported various religious groups such as Buddhist, Muslim and other religious groups which are not specifically associated with ethnicity; 10% reported Middle Eastern groups; and 24% reported other groups such as South Africans and Aboriginal Australians.[53]



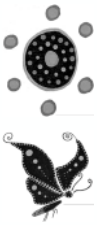
What are some starting points?



ALOs should be better supported through formal supervision and emotional or counselling support.[60]



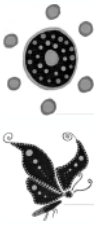
For workers who have already graduated, palliative care information and awareness programs should be developed. These might include local service providers identifying and making contact with these workers and providing in-service training, information sessions and work experience opportunities.[61]



Provide introductory training in palliative care concepts and approaches for Indigenous Australian staff in mainstream services and Indigenous Australian organisations.[64]



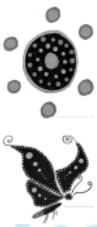
Cultural awareness courses should be tailored for palliative care workers.[62]



Establish relationships with Indigenous Australian organisations and personnel to facilitate the delivery of training which is locally relevant.[65]



Reflect on personal and organisational practice in the context of the training provided.[63]



Specific training and positive experience with each cultural group is necessary to increase feelings of competence.[66]

Ideas, comments, strategies, activities ...

Ideas, comments, strategies, activities ...



Improving the planning and delivery of palliative care to Aboriginal and Torres Strait Islanders in NSW

This section of the Workbook provides examples from research about improving the planning and delivery of palliative care to Aboriginal and Torres Strait Islander people in NSW.

Improving the planning and delivery of palliative care to Aboriginal and Torres Strait Islander people in NSW has some starting points for discussion of strategies and activities that will enhance the provision of palliative care to your local Aboriginal and Torres Strait Islander community. The starting points in bold lettering are from the *Resource Kit: providing culturally appropriate palliative care to Indigenous Australians*. Please refer to the Kit for more information. Icons (butterfly and flower) are used to indicate personal and organisational starting points. Writing space is provided on the following pages for jotting down ideas. You can use your ideas and comments to develop strategies and activities that are specific to your local population and improve the wellbeing of people who live in your area.

Consider the Workbook as a living document. The ideas you develop today will probably evolve over time, so revisit your jottings on a regular basis. You may wish to make discussing ideas for improving the planning and delivery of palliative care to local Aboriginal and Torres Strait Islander people part of regular staff meetings.

Planning and delivery of care: What does the research show?

A significant issue is that there is inadequate time for a palliative care team to develop a relationship with the client and the family. This generally takes longer with Aboriginal families than with other cultural groups, because of past negative experiences, and the history of suspicion of non-Indigenous services and fear of (non-Indigenous) authority. Many Aboriginal people believe that mainstream service providers will not take the time that will be needed.[68]

Suitable places for large groups of people and access to outdoor spaces are very important to Aboriginal and Torres Strait Islander patients and their families.[69]

Discharge planning has been very inadequate. One Aboriginal client with long term post-operative special dietary needs was discharged without the hospital checking the availability of the dietary supplement or the patient's ability to afford it. It is quite likely that (other) Aboriginal clients are not receiving the referrals that they should have.[70]

There is general and strong agreement that the place of death should be the choice of the individual and their family.[71]

An AHW in New South Wales said 'Where a person is buried is almost more important than where they die.'[72]

A terminally ill man explained that to 'die away from family' is to 'be separated from family in death'.[73]

Not enough (often no) Aboriginal staff except perhaps an ALO, even in areas with a relatively high Aboriginal population (for example a town where the Aboriginal population is 13% of the total has only one ALO and she is the only Aboriginal employee in the hospital). 'Just having some black faces makes a great difference'.[74]

In general, Aboriginal and Torres Strait Islander people strongly dislike, distrust and fear hospitals and non-Indigenous strangers coming to their homes.[75]

"Most palliative care services had little or no knowledge of Indigenous services and no contact lists for services such as Indigenous home care or HACC services, the Community Options Program, AMSs or other Indigenous groups or organisations in their regions ... None of the services we spoke with had recruited or aimed to recruit Indigenous volunteers."[76]

What are some starting points?



A number of protocols need to be developed on a local and regional basis to allow adequate care planning to develop.[82]



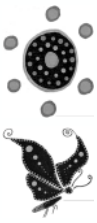
Better coordination between the hospital and the palliative care service (home-based, hospital-based or hospice-based) to try to develop continuity from referral, through discharge to assessment and service delivery.[83]



Involve Aboriginal and Torres Strait Islander service providers and family members in discharge planning, care planning meetings and case management meetings.[84]



The palliative care team in a New South Wales rural town suggests working with the community to develop appropriate bereavement strategies for Aboriginal family members in order to offer appropriate support.[85]



Support the inclusion of traditional practices where requested by the patient and/or family. This may include working with traditional healers or Elders to provide traditional healing and singing, provision of traditional foods and supporting the practice of traditional ceremonies.[86]

Ideas, comments, strategies, activities ...

Planning and delivery of care: What does the research show?

One woman commented that she was 'not game enough' to ask hospital staff if she could use the local ambulance for transport to hospital for treatment 'like the other patients [non-Aboriginal] do.[77]

In most instances, the family followed the terminally ill person to the metropolitan hospital for as much of the hospitalisation as possible. This placed enormous financial and emotional burdens on the family members, some of whom had never been to a city before.[78]

In some instances, the experience of transfer to a metropolitan hospital was so alienating for both the terminally ill person and their family and the 'longing for home' so intense that patients discharged themselves and returned home without completing their treatments, vowing never to return to the city again.[79]

Participants spoke of the lack of communication between rural and metropolitan health service providers.[80]

The remoteness of terminally ill Kooris in relation to the point of service delivery causes lots of problems. Public transport is sometimes the only means for patients to access services but is often inappropriate for those that are terminally ill.[81]



What are some starting points?



Two projects have been funded recently to look specifically at Aboriginal grief and loss issues: one in Victoria, managed by VACCHO; and one in New South Wales, managed by New England Community Health.[87]



It would be really good if there was a booklet that covered what to expect – what to expect at the time of death – and there are also things that you don't know, like what to do after a person dies – where you can get support, where you can get help with a funeral, who you need to contact – like the tax office, the electoral office, etc. [community member][88]



Volunteer manuals need to be revised to include sections on working in cross cultural environments.[89]



Identify and resource an Indigenous Australian (or person with Indigenous Australian cultural safety training/experience) to work with the organisation as a link between the patient, staff and support services.[90]



Consider the impact of one's own culture and values on the provision of care to the Indigenous Australian person, their family and community.[91]



Provide adequate information about the patient's/family's cultural requirements to staff and volunteers involved in the care.[92]

Ideas, comments, strategies, activities ...

Ideas, comments, strategies, activities ...



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6 Collis-McAnespie C, Hemmings P, Bell L and Dawes A, op cit, p22.

7 ibid, p23.

8 ibid, p25.

9 ibid, p29.

10 ibid, p34–35.

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