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Commissioning for long term conditions: hearing the voice of and engaging users

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Commissioning for Long Term Conditions: Hearing the voice of and engaging users

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1 Research summary

Objectives

Over the past few years there has been an increasing recognition that the NHS needs to improve the support and service it provides to people with Long Term Conditions (LTCs). The current context for this is within a framework where commissioners are expected to develop stronger roles in shaping and planning local services that are responsive to local needs. In relation to long term conditions policies of choice and patient and public involvement are key to how this will be achieved. The aim of this research will be to examine how commissioners enable voice and engagement of people with Long Term Conditions and identify what impact this has on the commissioning process and pattern of services. A key outcome of the research will be guidance (a 'road map') for commissioners on the skills and expertise needed by different commissioners, what actions are most likely to lead to responsive services and the most effective mechanisms and processes for active and engaged commissioning for people with long term conditions.

The specific objectives are to:

1. Critically analyse the relationship between the public/patient voice and the impact on the commissioning process
2. Determine how changes in the commissioning process reshape local services.
3. Explore whether any such changes in services impact on the patient experience
4. Identify if and how commissioners enable the voice and engagement of people with LTCs.
5. Identify how patient groups/patient representatives get their voice heard and what mechanisms and processes patients and the public use to make their voice heard.

Research design

The research will adopt a multi layered approach at national, SHA and local PCT levels combining national mapping of activity, analysis of local context at the SHA and PCT level and detailed case studies in three locations using qualitative methods. Our central aim will be to explore the nature of engagement between patients/service users, the public and local NHS organisations within their specific context. The level of influence on local commissioning decisions made within PCTs, Hospitals and other NHS and social care services will be examined. Case study research[1 2] provides the opportunity to collect and analyse data at both the exploratory and the explanatory level within the local context. By undertaking a wider mapping of activities across all PCTs and within three specific SHAs the research will be able to examine and identify the relationships between national policy and local developments.
Three case study areas will be selected from three SHAs to provide a range of demographic and geographical variation. The study will focus on three LTCS that reflect different population groups and varying relationships across the health and social care divide and demand for services. These are:

1. Diabetes
2. Rheumatoid arthritis
3. Neurological conditions

The research will be conducted in five phases over 45 months.

Phase one

This phase aims to establish a compendium of current practice in commissioning for LTCs. A scoping of national changes in commissioning will be undertaken. Data from other studies of commissioning and changes in services across the country such as Department of Health pilot sites and demonstrators will be drawn upon. PCT, SHA and national patient organisation websites will be examined, and a documentary analysis of policies, budgets, commissioning power and how choice sets[1] are developed for the selected LTCs will be completed. The findings from this phase will be used as a basis for statements in an adapted likert scale[4 5] to be used in subsequent phases.

Phase two

This phase aims to contextualise the specific range, type and actions of groups that will be examined in phase three. Detailed information on the three case study sites will be collected through a participative workshop for local commissioners and patient representatives and will identify local NHS organisations, public and health consumer groups and other relevant voluntary sector groups in the area. Through purposive sampling the following will be selected for a semi structured individual or group interview:

1. 5 practice based commissioners
2. 2-3 PCT commissioners and patient and public involvement staff
3. 1 provider for each condition
4. 3-5 patient groups per site representing each tracer condition.

A subsequent workshop will be held in each site and will draw on the issues raised in the interviews. The workshop will particularly focus on exploring patient pathways and defining choice sets for services. Local commissioners, clinical leads and patient organisation representatives from the three tracer conditions will be invited.

Phase three

The aim of phase three is to identify the impact of involvement on local health policy processes such as service reconfiguration, delivery and development. From the results of preceding phases up to two tracer conditions will be focused upon in each case study site. The main method of data collection will be through monthly contact with a purposive sample of up to 3 individuals from each site together with the collection of relevant documentation and observation of key meetings. These key informants will be interviewed after the workshop and then twice more over an 18 month period. Focus groups with a purposive sample of local patient and public groups will also be held every six months during this phase. Both the interviews and focus groups will draw upon a methodology based on Rifkin's star point likert scale[4 5]. This will be used to assess and compare perceptions of engagement in commissioning.

Phase four

Following an initial analysis of data in phases two and three, two summative focus groups of commissioning/provider staff and patients in each site will be held. This phase will identify outcome measures relating to commissioning including direct evidence of service change. An expert reference group of clinicians will advise on the likely clinical impact of service change related to commissioning practice.

Phase five

Feedback from the expert reference group and the preliminary findings will be used for discussion and clarification in a workshop for public representatives and commissioners from all three sites. The workshop will be used to refine patient pathways and choice sets and identify the most effective and valuable

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[1] Choice sets are the range of services for one LTC or need from which a service user may choose. This term is also known as "meaningful menu"3. Department of Health. *Generic choice model for long term conditions*. London: Stationary Office, 2007.

approaches to patient and public engagement that inform commissioning processes.

Expected outcomes

It is expected that the project will identify ways of engaging with local groups more effectively and provide details of the kinds of processes that are likely to lead to satisfactory outcomes and responsive services. The nature of the study will provide lessons for both statutory services and local patient groups. Local groups will be worked with to support development of engagement activities and facilitate engagement providing useful insights to commissioners in other areas. Benefits will be in terms of both process and outcomes.

2. Background

There is a growing recognition that the NHS has not provided sufficient support to people with LTCs nor managed their care to their, or the NHS's benefit. About 30% of the population identify themselves as having a chronic health problem and account for 52% of all GP visits, 65% of all hospital outpatient appointments and 72% of inpatient days[6]. In addition, the 15% with three or more co-morbidities account for 30% of inpatient days. There is also a growing recognition of the increasing numbers of children with LTCs[7,8]. People with LTCs experience poor co-ordination of care, leading to adverse events and increased hospitalizations. International comparisons suggest that the UK lags behind other countries in supporting people with LTCs[9,10]. Since the NHS Plan the government has been committed to improving support for people with LTCs and set public service agreements in 2005 to reduce emergency bed use and introduce case management for high intensive service users[6,11-14]. A key policy theme has been enabling ‘person-centred' or ‘personalised' care[15].Commissioning is central to this process and to the achievement of policy on LTCs[16]. Yet commissioning for health, and in particular, commissioning in the NHS has received much criticism[17-19]. Research highlights the need for substantial management investment and a range of needs assessment, clinical, contracting and relationship management skills[17,18,20-22]. In the context of commissioning in the English NHS it is unlikely that there will be additional investment in expanding commissioning management as concern has been expressed about whether the additional cost will produce sufficient gains in productivity[19]. Commissioners will need therefore to demonstrate how they can achieve maximum benefit within existing resource levels by focusing activities on those that bring most patient benefit. One approach currently under discussion is greater integration of health services along the lines of USA integrated purchaser/provider models or making greater use of soft methods of persuasion [6,19]. Emphasis is placed on developing choices by engaging local users and organizations for people with LTCs, rather than as individual patients, to ensure an appropriate range of services that meet people's needs [3]. The DH consultation on choices for people with LTCs focuses on shifting away from a "one size fits all" to one maintaining independence and providing people with more choice and control over their care with benefits for patients and the NHS[3]. However, with regard to people with LTCs the emphasis is on developing clinical pathways and care management programmes[6,23]. To date there is insufficient evidence of the effectiveness of such approaches in many chronic conditions[24-28], or any evidence of significant service user input influencing the development of pathways[29,30]. The development of pathways may also create tensions with policies on choice and it would seem critical that to develop responsive pathways that provide meaningful choices will require significant service user input as well as collaboration with health care commissioners and providers[3,23,31]. While formal mechanisms for patient and public involvement have been established[32,33], there is area wide variety of patient and user organisations at a local level. Patients, users and carers with a collective illness identity[34,35] have long organised themselves often independently of government but these organisations are diverse and hence difficult to categorise and analyse[36]. Research suggests that local organisations are often patchy in coverage[36 37], although at a national level groups such as Carers UK, National Voices (formerly the LMCA) and the Patients Forum are closely involved in the policy process and some support local group engagement with the NHS and social services[36]. Specific case studies of HIV/AIDs groups, maternity, physical disability and mental health users suggest that local groups do get engaged in policy and service issues and that patient/advocacy and voluntary organisations are important in promoting patient and public involvement with the NHS[38-42]. Such investigations have, however, paid relatively little attention to the outcomes of patient and public involvement[43].

While the importance of patient and public involvement in commissioning has been recognized since the initial development of NHS purchasing in the 1990s there has not been any significant evidence that such engagement has influenced commissioning decisions[41 43-45]. The Picker Institute's recent survey found that while PCTs had a number of mechanisms and defined management responsibilities for patient and public involvement "..there is a disconnect between these activities and the relatively low expectation that patient, public and community groups will have significant influence on commissioning decisions"[44]. Key barriers identified were difficulties in reaching marginalised, isolated or deprived groups, a lack of understanding amongst the public of "commissioning" and a lack of reliable data about patients' experiences. However, when asked what approaches PCTs were considering for future engagement there was a continued emphasis on methods such as formal consultations, patient panels, citizen's juries, and surveys. Yet current proposals for people with LTCs suggest that user groups will be key in the increasing devolution of decisions to practice-based commissioners and the development of ‘strategic commissioning' between health and social care agencies[16]. Guidance for commissioning agencies published in 2007 places great importance on how commissioners can procure care that promotes the health and well-being of individuals in consultation with local people[46]. These have now been incorporated into the new commissioning competencies, needs assessment frameworks and performance regimes across health and social care[31 47] and there is a clear emphasis on increasing the role of the third sector[48]. *The NHS Next Stage Review* highlights changing public expectations related to ‘control, personalisation and connection', and building partnerships with patients and LTC user groups[49]. Emphasizing the role of incentives in improving quality and performance and new regulatory arrangements from April 2009 will also mean that organisations across a local authority area will be jointly held to account for performance in relation to shared targets within Local Area Agreements[31]. While the policy direction for commissioning is clear, implementation is variable as PCTs cope with a complex blend of incentives and regulatory arrangements. Practice based commissioning (PbC) is integral to the success of commissioning strategies for LTCs but remains underdeveloped as it has ‘yet to have a significant effect on the redesign of services' and that ‘the incentives and infrastructure to support PbC are not currently sufficient to engage most GPs in commissioning'; a finding supported by recent research on PbC[50 51]. Moreover, without strengthened commissioning and greater emphasis on the demand side the current transformation programme will not provide ‘the necessary balance of power between primary and secondary care'[52]. In addition commissioners will need to consider what impact the recent proposals for personalised budgets will have on the commissioning process. Good commissioning for people with LTCs will require developing not only a set of skills for commissioning responsive and appropriate patient pathways that provide relevant choices for service users but also developing approaches to sustaining user engagement. Existing research on engaging users in the NHS and on user involvement in change management in health services demonstrates a willingness and commitment to engagement but few, if any, concrete examples of effective influence by users or evidence of change[43 44]. In addition a recent survey of national patient groups (supervised by Peckham) found little engagement with choice policy or support for local groups. Therefore, this project will contribute directly to supporting the development of relevant skills, mechanisms for engagement and areas of action for both commissioners and service user organisations. In particular, three areas will be identified of activity in relation to patient and public involvement relating to direct action by commissioners, facilitative action and regulatory action and how and when each of these approaches provides the most effective patient and service outcomes.

3 Aims

The aim of this research will be to examine how commissioners enable voice and engagement of people with Long Term Conditions and identify what impact this has on the commissioning process and pattern of services. A key outcome of the research will be guidance (a ‘road map') for commissioners on the skills and expertise needed by different commissioners, what actions are most likely to lead to responsive services and the most effective mechanisms and processes for active and engaged commissioning for people with long term conditions. Our specific objectives will be to:

1. Critically analyse the relationship between the public/patient voice and the impact on the commissioning process
2. Determine how changes in the commissioning process reshape local services.
3. Explore whether any such changes in services impact on the patient experience
4. Identify if and how commissioners enable the voice and engagement of people with LTCs.
5. Identify how patient groups/patient representatives get their voice heard and what mechanisms and processes patients and the public use to make their voice heard.

4 Research Design

The research will adopt multi layered approach at national, SHA and local PCT levels combining national mapping of activity, analysis of local context at the SHA and PCT level and detailed case studies in three locations using qualitative methods. Our central aim will be to explore the nature of engagement between patients/service users, the public and local NHS organisations within their specific context[2 53]. We will examine the level of influence on local commissioning decisions made within PCTs, Hospitals and other NHS and social care services. Case study research provides the opportunity to collect and analyse data at both the exploratory and the explanatory level within the local context. By undertaking a wider mapping of activities across all PCTs and within three specific SHAs the research will be able to examine and identify the relationships between national policy and local developments. The research team have experience in this approach both in current studies on CDM and patient choice and in a range of other studies concerned with social phenomena in health and social care settings.

Three case study areas will be selected following our initial scoping to reflect innovation in commissioning, and or PPI/LTCs. The case study areas will provide a range of demographic and geographical variation including urban/rural disadvantaged and non-disadvantaged communities, and different ethnic and cultural populations and a range of local NHS agencies and coterminous PCT/Social Care arrangements. The study will focus on three LTCS that reflect different population groups and varying relationships across the health and social care divide and demand for services. These tracer condition groups are:

1. Diabetes (vocal patient groups, large population, established services)
2. Rheumatoid arthritis (less established patient groups & services)
3. Neurological conditions (Variety of patient groups and services with substantial local variation in services).

All age groups will be included as there is increasing concern over the experience of children and young people with LTCs and the impact on their families. These young people are even less likely to have a voice in their health care than adults with LTCs. The project team is committed to working participatively with organisations in the case studies. We will establish a project website and develop Google discussion groups with local representatives. For younger people we will establish a ‘MySpace' or Bebo page moderated by one of the research team members with expertise in developing digital media work with young people.

5 Methodology

Social research methods employed by case study researchers to undertake in-depth, mainly qualitative evaluations of policy and health care delivery processes will be used. A range of techniques will be employed to address the objectives of the study, providing rich data from which logical conclusions and theoretical generalisation can be drawn. Specific methods include interviews, group work and workshops, observation, collection and analysis of documentary data and the use of innovative data collection tools to assess dimensions of participation. Working with user representatives both textual and visual approaches will be developed to represent issues as we will be working with groups of users throughout the lifespan with a range of written and communication skills.

The research will be undertaken in five phases.

5.1 Phase One

November 2009-August 2010. Scoping of national changes in commissioning

We will draw on data from other studies of commissioning and changes in services across the country such as SDO Self Care, Chronic Disease Management, Department of Health pilot site evaluations and demonstrator sites. We will examine PCT websites, project websites, contact national patient organisations and contact regional and SHA co-ordinators. It will also involve a documentary analysis - policies, budgets, commissioning power and how choice sets are developed for the selected LTCs. The aim will be to establish a compendium of current practice in commissioning for LTCs. Data gathered during this phase will be used to construct statements in an adapted likert scale[4 5] which will be used in subsequent phases to track changes in perception of user involvement, and to provide a visual aid to trigger discussion in focus groups and workshops. A young person's reference group will be set up to specifically adapt the tool for younger people.

5.2 Phase Two

November 2009-October 2010. Contextualisation of the case study sites

This phase aims to contextualise the specific range, type and actions of the three tracer condition based groups (diabetes, rheumatoid arthritis, neurological conditions) that will be examined in more depth in the next phase.

Exploratory workshop

Detailed information on each case study site will be obtained by a participative workshop using open space methodology[54] with local commissioners and patient representatives. The results of the workshop will enable a mapping of the tracer condition groups, institutional structures, public and health consumer groups, and other relevant voluntary sector groups. The workshop will also provide detail on the local context and analysis of the internal and external levers on commissioners in each case study site.

Interviews Individual semi-structured interviews will be undertaken with commissioners and patient representatives. The interview guide (annex 1) will aim to elicit views on the issues, processes and current activity relating to commissioning for people with LTCs in each case study site and across the three tracer conditions. At the end of the interview, participants will be asked to complete a likert scale tool based on Rifkin's approach [5] to measure interviewees' perceptions of user involvement. Participants will be purposively sampled and will include the following:

- 5 practice based commissioners
- 2-3 PCT commissioners and patient and public involvement staff
- 1 provider for each condition
- 3-5 service users groups representatives per site representing each condition.

Focus group
A focus group will be held in each site with younger people as this is a well established method of eliciting views from this particular group of service users[55]. The focus group guide (annex 2) will aim to facilitate discussion on young people's views on issues, processes and current activity in taking their viewpoint into account during the commissioning process. Data from the focus group will be drawn upon to develop vignettes that will be used as triggers for discussion in phase three focus groups. At the end of the focus group, participants will be asked to complete an adapted likert scale tool based on Rifkin's approach [5] to measure interviewees' perceptions of user involvement. For younger people that would prefer to talk to researchers individually, an interview (either face to face or by telephone) will be offered as an alternative to the focus group.

Focused workshop
We will select a sample of issues identified by local users from the interviews in the case study areas to provide the basis for a workshop in each of the three cases studies. The workshops will explore these local issues and approaches to commissioning for people with LTCs in more depth. A particular focus of the workshops will be to explore patient pathways and focus on defining 'choice sets' for services. We will invite local commissioners (PCT, PbC/CCG, Local authority) and clinical leads (commissioner, provider), representatives from patient organisations in the three tracer conditions and representatives from key consumer/patient organisations (LINk, local forums, CVS etc).
We will use the workshop to identify two specific tracer conditions groups per case study site for ongoing in depth analysis in phase three. We will produce a workshop report that highlights key issues and approaches as an interim output from the project and make this available to workshop participants. We will also place a copy on the project website so that it can be accessed by other commissioners and patient organisations.

5.3 Phase Three

November 2010-December 2012: Evaluation of the impact of involvement on local health policy processes.
The aim of phase three is to identify the impact of involvement on local health policy processes such as service reconfiguration, service delivery, and service development. We will explore public/patients' and commissioners' views and perceptions of how the public voice is heard and if/how it impacts on change. This will focus on examining processes related to two condition areas in each case study identified from the workshops in phase two. We will focus on particular patient pathways or a limited number (depending on size and complexity) of specific pathways for the selected conditions. Participants will be asked to identify issues and the extent to which they have successfully influenced local health policy processes in the past year, and issues that they are currently trying to place on local policy agendas and /or attempts to influence current commissioning policy/strategies on LTCs.

Interviews
A purposive sample of three key informants (service user representative, commissioner, service provider) per case study site will be selected. They will be interviewed immediately after the focused workshop in phase two and then twice more over the next 18 months (annex 3). As in phase 2, at the end of each interview, participants will be asked to complete a star point scale tool based on Rifkin's approach [4 5] to measure interviewees' perceptions of changes in user involvement. In addition, the key informants will be telephoned on a monthly basis to track case study site activities in involvement (annex 4).

Focus groups

We will select local public/patient groups through purposive and snowballing sampling procedures to ensure adequate coverage of a range of patient groups. Representatives from these groups will be asked to complete the star point scales and these will be used as a trigger for focus group discussions. Participants will be asked to complete the star point scales (annex 5) at six monthly intervals which will provide a visual record of changes. Separate focus groups or interviews will be held with younger people. Vignettes developed from phase two will be used to trigger discussion on their involvement in LTC service commissioning. An adapted version of the Rifkin star point scale will be emailed to the younger people every six months to track their perception of changes in user involvement.

Observation and documentary analysis

In each site there will be non-participant observation of 2-4 key commissioning meetings together with the collection of relevant documents for analysis. Field notes of the meetings will be recorded.

National survey of Clinical Commissioning Groups (CCGs)

This will be conducted collaboratively with the Policy research Unit in Commissioning and the Healthcare System (Director Stephen Peckham). The research team are contributing questions on PPI to this national telephone survey.

5.4 Phase Four

January 2013-March 2013: Confirmation of outcome measures

Following an initial analysis of data from phases two and three, the aim of this phase is to identify outcome measures related to commissioning including; direct evidence of service change, changes in investment, satisfaction with such changes and processes of engagement.

Clinical opinion will be sought from an expert reference group to evaluate whether the actual or proposed changes are likely to lead to improved patient outcomes.

Focus groups

Summative focus groups will be held respectively with a purposive sample of commissioning/provider staff, and service users in each case study site. Discussion will focus on satisfaction with the changes in services and processes of engagement (annex 6).

Documentary analysis

Examination of CCG achievements in 2012/13 and review of plans for 2013/14.

5.5 Phase Five

April 2013-Julne 2013: Summative workshop

In the final phase we will bring public representatives and commissioners from all three case studies together in a workshop to present findings, assess current situation and look to the future. We will present our preliminary analysis for discussion and clarification. We will use the 'star' diagrams to stimulate debate and discussion and represent material on patient pathways from the original workshops in each location. Younger people and parents will be invited to attend before the main workshop so that findings can be presented in an accessible way. If they wish, they will be able to attend and participate in the main workshop. We will use the workshop to refine patient pathway and 'choice sets' and identify the most effective and valuable approaches to patient and public engagement that inform commissioning processes. The data from this workshop will be used to refine our analysis and produce guidance, or a road map, for commissioners and local patient groups on engagement processes and how to maximise patient and public engagement to support effective commissioning for people with LTCs.

6 Sample

Inclusion & exclusion criteria

We will include;

- Service users and representatives from age **12** - no upper age limit, with diabetes or rheumatoid arthritis or a neurological long term condition receiving services in the case study site (PCT)
- informal carers
- Parents of children 0-16 years old

We will exclude;

- Younger people whose parents/guardians do not consent to the younger person's participation
- Service users & informal carers who are unable to speak or read English and for whom translation services within the research team or locally are unavailable,
- Informal carers of adult patients who have not consented for the carer to be approached

Interviews

- **NHS staff**
  In phase two we will interview up to 5 practice based commissioners, 2-3 PCT based commissioners and public involvement staff, and 1 provider in each case study site (n=24-27). In phase three we will interview 3 key informants in each site (n=9).
- **Service users and representatives**
  In phase two we will interview 3-4 service users or their representatives in each site (n=9-12).

Focus groups

- **Service users and representatives**
  In phase two we will conduct 1 focus group with 6-10 young people per site (n=18-30), in phase three 3 focus groups with 6-12 adult participants per site (n=54-108), in phase four 1 focus group with 6-10 young people per site (n=18-30) and 1 focus group with 6-12 adult participants per site (n=18-36).

Observation

We will observe 2-4 meetings per site.

Workshops

- **NHS staff**
  In phase two, 2 workshops will be facilitated for 8-14 commissioners and providers per site (n=24-42). In phase five, 15-25 commissioners and providers will be invited to a summative workshop (n=15-25).
- **Service users and representatives**
  In phase two, 2 workshops (as above) will be facilitated for 5-10 service users and representatives per site (n=15-30). In phase five, 15-25 service users and representatives will be invited to a summative workshop (n=15-25).

7 Analysis

Comparative case-study analysis seeks to identify and explain patterns across and within organisations and case-study sites. The analysis strategy will be

a) to observe, describe and explain the interaction between commissioning approaches identified in phase two and the way public and patients are engaged in such processes;
b) to identify and explain patterns of LTC commissioning in each case study;

c) to examine the relative influence of p
commissioning processes to identify
and practice. The analysis will be str
identified above, using Ritchie and S
research[56].

Extensive notes will be made of workshops
and analysed by the research team. Intervie
and explored to uncover main themes. Trans
members, their content being organised into
former will largely reflect the interview topics
to compare inter-rater reliability; differences
project team meeting and a common themat
findings are empirically grounded. Transcrip
VIVO) to enable thematic coding. Document
and decisions made. Visual 'starcharts'[4] will
measurements and also retained as visual r
discourse analysis of written documents and
service changes using local service data fro
investment plans etc.

Analysis will focus on developing recommen
contributing to an understanding of the proce
highlighting inter-relationships between cont
the local policy agenda. Workshops in phase
area utilising initial analyses of the case stu
help validate our analyses but also to act as
based on participant critiques of and reflecti
analyses will be informed by a number of st

8 Ethical issues & public involvement

No major ethical issues are anticipated. How
for patients and carers the experience of livi
Members of the team undertaking the intervi
be able to suggest appropriate sources of s

The invitation letter, information sheet, resp
will be sent out by each NHS site or patient
with a covering letter. The research team wi
of each participant once the response form
will be accessed by the research team.

Written, informed consent will be taken from
and focus groups.

In terms of the focus groups or interview for
discussion will be about the experience of b
and how they feel their views are taken into
"distressing" experiences. It will be importan
centred strategies for reinforcing messages
parameters of confidentiality, including the r
we will agree with the young people a form
wish to leave the focus group/interview or st
and Save the Children indicate that research
young people to de-brief after the focus grou
the researcher being available informally aft