

○ Patient involvement in health care

MEMORANDUM TO THE HOUSE OF COMMONS
SELECT COMMITTEE ON HEALTH: INQUIRY INTO
PUBLIC AND PATIENT INVOLVEMENT IN HEALTH
CARE

10TH JANUARY 2007

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Memorandum to the House of Commons Select Committee on Health

Re: inquiry into Public and Patient Involvement in the NHS

Summary

1. Picker Institute Europe welcomes the Select Committee's Inquiry. Based on its evidence of patients' experience in their NHS treatment and care, the Picker Institute urges the Committee:
 - to support and promote the continuation of the national patient survey programme under the future regulator
 - to examine the best means to require trusts to demonstrate that they are involving patients in using survey results for quality improvement
 - to consider whether the Local Government and Public Involvement in Health Bill should be amended to enable the Secretary of State, through regulation, to impose such a duty on trusts
 - to recommend to the Secretary of State the amendment of Section 155 of the Local Government and Public Involvement in Health Bill so as to include a power for the Secretary of State to impose duties:
 - to publish and share promptly with relevant LINKs the information from patient surveys
 - to assist LINKs to analyse and understand that data
 - to involve LINKs in the design and commissioning of future patient surveys.
 - formally to welcome the new approach to patient/professional partnerships encoded in '*Good Medical Practice*'
 - to examine ways in which this partnership approach can be pursued, especially via education, training and continuing professional development, to ensure doctors uphold the *Good Medical Practice* standards
 - to recommend to the government that similar processes of revision should be forcefully pursued through the other health professions
 - to recommend to those professions that they adopt approaches to patient/professional partnership reflecting the new *Good Medical Practice*
 - to highlight to government and to the relevant health professions the priority need to develop up to date and effective models for patient feedback questionnaires relating to professional performance

- to recommend to the government and relevant health professionals that these feedback mechanisms be built into the current and forthcoming revisions to professional appraisal and revalidation systems.

2. About the Picker Institute

- 2.1 The Picker Institute is an independent health charity which works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice.
- 2.2 It undertakes a unique combination of research, development and policy activities which together work to make patients' views count. These include:
 - Researching and evaluating patients' experiences
 - Leading initiatives that make improvements happen
 - Building evidence to inform health policy.
- 2.3 The Picker Institute led the development of patient experience surveys in the UK. These go beyond simple measures of 'satisfaction', by enabling patients to report on their actual experience of various aspects of their care and treatment. The questionnaires are developed through holding focus groups with relevant patients to discover what aspects of care they focus on the most, followed by large scale surveys of patients, producing results which enable health professionals and managers to identify areas for improvement.
- 2.4 There is now a Department of Health requirement for every NHS trust to carry out an annual survey of patients. The Picker Institute is an approved provider of surveys for this programme, and acts as the national co-ordination centre for all the surveys carried out by acute trusts. The Picker Institute also provides bespoke survey services to NHS bodies and other organisations, including staff surveys as well as patient surveys. On the basis of this evidence and its other, independent research, the Picker Institute works to improve the quality of patient care with a variety of organisations involved in the NHS, in professional regulation and in representing patients' views. It is consulted frequently by government and the Department of Health, as well as relevant All Party Groups in parliament.
- 2.5 The Picker Institute is not an organisation run for or by patients, but an independent charity with unrivalled research and practical knowledge of what patients say they experience in the NHS. This memorandum makes use of this evidence base to address the issue of 'patient involvement', arguing that this should be seen as, in many respects, distinct from the question of 'public involvement'. The Picker Institute does work closely with organisations run for and by patients, and is an associate member of the Patients Forum, and would additionally support many of these organisations' inputs to this Inquiry.

Answers to the Inquiry questions

3. What is the purpose of public and patient involvement?

Distinguishing 'patient' from 'public' involvement

- 3.1 Like the Long-term Medical Conditions Alliance (LMCA), the Picker Institute believes the primary purpose of public and patient involvement should be to achieve a truly patient-led NHS.
- 3.2 However, although government and NHS policies and plans lump 'public and patient involvement' together, the Picker Institute's experience is that they need to be distinguished from each other, rather than conflated. One result of their conflation is that, while there have been a number of initiatives to establish public involvement, the latest of which is the Local Involvement Networks, there has been little attention to tackling what **patients** say they want.
- 3.3 Patients – that is, people who are or have recently experienced NHS care -- and 'the public' express different viewpoints about the NHS. The Populus study, which tracked the perceptions of 2,000 respondents representative of the population as a whole during 2005, was typical of all research studies in finding that:

"patients are generally more positive about the NHS than the population as a whole, exhibiting larger majorities in favour of the propositions that the NHS is improving, that it provides a good service overall and that it is at least as good as health services abroad" ¹

- 3.4 In part this is because the general population is more influenced in its perceptions by the media, hearsay and political opinions, whereas patients respond on the basis of their actual experiences of care. But there is a more important general truth: **patients care more about the quality of their own treatment, and therefore their interactions with the service and with health professionals, than about how the service is organised**; while citizens are more likely to address collective or societal issues of the organisation of health care, such as the pattern and nature of health care provision.
- 3.5 While we are all both citizens and patients (or potential patients) it is important to try to disaggregate the 'public' and 'patient' approaches to involvement. In a recent attempt to start this debate², the Picker Institute suggested some distinctions between what patients and citizens want from the NHS:

¹ 'What patients really want', Populus, 2005, ISBN 0-9548552-1-3

² 'Healthy Democracy: the future of involvement in health and social care', Involve and the NHS National Centre for Involvement, 2006, ISBN 1-12345-123-1

PATIENTS	CITIZENS
Fast access to reliable health advice	Affordable treatment and care, free at point of use
Effective treatment by trusted professionals	Safety and quality
Shared decisions and respect for preferences	Health protection, disease prevention
Clear information and support for self-care	Accessible local services + centres of excellence
Attention to physical and environmental needs	Universal coverage and equity
Emotional support, empathy, respect	Responsiveness, flexibility, choice
Involvement of and support for family & carers	Participation in service development
Continuity of care, smooth transitions	Transparency, accountability and opportunity to influence decisions

- 3.6 While this table is intended to stimulate further debate rather than to be conclusive, the eight terms in the 'patients' column here are **definitive**. These are the eight key areas of focus identified by patients' reporting of their own experiences of care in all the national patient experience surveys carried out for the NHS since 1998.
- 3.7 Although the terms in the 'citizens' column, and the exact nature of overlaps and distinguishing points may be open for discussion, the key point is that patients have defined what they want from NHS treatment and care, and it is qualitatively different to the collective aspirations that citizens or the general public might hold.
- 3.8 With regard to the 'purposes' of involvement, therefore, there should be two sets of related, and at times overlapping, but necessarily distinct discussions. If one 'purpose' of involvement should be to ensure that the NHS is accountable, for example, then this is likely to relate much more to public than to patient involvement. By contrast, if one 'purpose' is to improve the effective delivery of care by health professionals, this is more likely to relate to patient involvement.
- 3.9 Looked at from another perspective, patient experience as reported by masses of patients themselves through the surveys, requires that we look at specific areas for

service improvement, which may be different from the priorities for action generated by public opinion as a whole.

Purposes of patient involvement

3.10 The greatest potential benefits from involving patients, as distinct from the public, would lie in improving the effectiveness of care and treatment through transforming the interaction between patients and health professionals.

3.11 There is a growing body of evidence to demonstrate what such a focus could achieve. Engaging patients in treatment decisions and in managing their own health care has been shown³ to:

- improve the appropriateness of care
- improve the health outcomes
- reduce risk factors and prevent ill-health
- lead to more cost-effective outcomes
- moderate demand
- improve safety
- reduce complaints and litigation.

3.12 This kind of patient involvement is fundamentally different to the involvement of the public in service design, resource allocation, or in accountability mechanisms. Engaging patients in treatment and self-care requires a change in culture from the paternalism which still characterises most transactions between patients and the NHS, to a 'partnership' approach in which patients are supported to engage in shared decisions.

3.13 Key elements of the partnership approach include:

- the communications skills and training of doctors, nurses and other health professionals and allied staff
- clear and comprehensible information which patients can trust, and which can be personalised to them
- an environment in which not only patients but also their carers and families feel comfortable and welcomed
- an approach to patients' care plans which takes full account of the fact that it is patients, outside of the short intervals in which they meet health professionals, who take responsibility for and manage their conditions, and which prepares and supports them to do that.

UK's record on patient involvement

3.14 There have been various attempts to promote public involvement in the NHS, most recently through initiatives like the CPPIH and PPI Forums, and now LINKs. By

³ The evidence for all of these effects is reviewed in 'Patient-focused interventions: a review of the evidence', Angela Coulter and Jo Ellins, the Picker Institute for the Health Foundation, August 2006, ISBN 0 9548968 1 5, available via the Picker Institute website

contrast there has been very little progress on promoting patient involvement. Success has been patchy and dependent on the enthusiasm of individuals rather than a national steer. Evidence from the patient experience surveys suggests that, while patients have experienced significant progress in the way some aspects of health care are managed and delivered, there has been little or no improvement in many of the eight key areas of focus outlined in 3.5 above. Moreover, international comparisons suggest that the UK has a significantly poorer record on patient involvement than other advanced industrialised countries.

3.15 In 2005 the Picker Institute reviewed evidence from the 19 national patient surveys that had been completed since 1998, involving more than one million patients⁴. Clear improvements over time had been experienced with regard to several of the areas targeted for action by the government and the NHS – including waiting times for GP and outpatient appointments, and faster access to cancer specialists, for example. Patients continued to express high levels of trust and confidence in health professionals.

3.16 However, in areas of focus for patients themselves, there had been little improvement over those seven years. For example, in the key area of involvement in decisions and respect for patients' preferences:

- in 2005, 69 per cent of primary care patients said they were definitely involved as much as they wanted to be in decisions about their care – fewer than in 2003 when the figure was 73 per cent. Only 59 per cent were involved as much as they wanted to be in medication decisions
- in 2004, 21 per cent of outpatients and 26 per cent of A&E patients said staff didn't always listen carefully to what they were saying – no improvement on previous years
- in 2004, only 53 per cent of inpatients said they definitely had a say in decisions about their treatment. For outpatients the figure was 70 per cent; for A&E patients 64 per cent; for coronary heart disease patients 64 per cent
- the proportion of cancer patients expressing satisfaction with their involvement in decisions fell from 89 per cent to 84 per cent between 2000 and 2004.

3.17 As another example, in the key area of 'clear, comprehensible information and support for self-care', there had been significant improvements in the provision of information to patients with cancer and coronary heart disease (both priority areas within the NHS plan), but there were still severe shortcomings more generally:

- in 2005, only 61 per cent of primary care patients said they received enough information about the possible side-effects of their medicines, the same proportion as in 2003
- in 2005, 43 per cent of stroke patients said they were not given information about dietary changes that might prevent another stroke, and 33 per cent said they were not given information about physical exercise
- in 2004, 40 per cent of inpatients, 37 per cent of outpatients and 61 per cent of A&E patients said they were not told about danger signals to watch out for – the same proportions as in previous years' surveys. Repeat surveys in 2005 again showed little change.

⁴ 'Trends in patients' experience of the NHS', Angela Coulter, Picker Institute Europe, 2005

3.18 To assess whether the UK is any better or worse in involving patients in their own care than other countries, the Picker Institute analysed data from six countries in 2004 and 2005 – Australia, Canada, New Zealand, Germany, the USA and the UK⁵. While none of these excelled in promoting patient-centred care, UK patients were receiving less support for engagement in their healthcare than in any of the other countries. Fewer UK patients were involved in treatment decisions; they were less likely to have been invited to review their medication or to have been given information about possible side-effects; they received less help with recovery and rehabilitation; and they were the least likely to report that their doctor had given them advice on preventing ill-health.

4. What form of public and patient involvement is desirable, practical and offers good value for money?

Evidence

- 4.1 The future of patient involvement depends critically on the continued compilation of an evidence base that can be used to analyse patients' experiences en masse, to identify areas for improvement, and to measure progress. The key to this is the national patient survey programme. This programme requires each NHS trust organisation to conduct an annual survey of patients' experiences. There are several main benefits.
- 4.2 The first benefit is that the results contribute to a national picture of the quality and effectiveness of health care. They go beyond simple measures of 'satisfaction' by breaking down the care experience into its various elements in order to identify the strengths and weaknesses of NHS care nationally – and therefore the potential targets for improvement -- through patients' own reported experiences.
- 4.3 The second main benefit is that they inform each trust of its own strengths and weaknesses in patients' eyes. Moreover, the results each trust receives can be 'benchmarked' against the national picture, showing how well the trust performs in each area vis a vis its peers. The straightforward statistic that, for example, 30 per cent of this trust's inpatients were given inadequate information to manage their own care upon discharge, will be given context by knowing that this placed it among the worst 20 per cent of trusts.
- 4.4 A third benefit of the existence of this system is that it makes available a set of resources and a 'market' of providers upon which NHS bodies can draw to conduct additional surveys of their users or client populations outside the national programme itself. For example, commissioners may ask a survey provider to help them identify the priorities of a particular patient group in their locality.
- 4.5 A fourth potential benefit of the evidence base is to feed into structures of public involvement. The Picker Institute suggests (see below) that the LINKs should make

⁵ 'Engaging patients in their health care: how is the UK doing relative to other countries?', Angela Coulter, Picker Institute Europe, 2006

regular use of the survey information to hold their local NHS providers and commissioners to account.

- 4.6 For these benefits, the programme is relatively cost-effective. It merely requires each Trust to spend a few thousand pounds annually on 'customer care' surveys which, as a ratio to their expenditure budgets as a whole, is probably minimal compared to customer care expenditure in other parts of the public sector, and certainly to private sector market research.
- 4.7 The national patient survey programme is, however, not secure. In its short lifetime of less than a decade it has already had three masters and is due to have a fourth, when the Healthcare Commission is amalgamated with the National Social Care Inspectorate and the Mental Health Commission.
- 4.8 The Picker Institute therefore urges the Select Committee:
- **to support and promote the continuation of the national patient experience survey programme under the future regulator.**

Using the evidence base (I)

- 4.9 Currently, however, the patient survey is open to the criticism that in itself it does not create change. There is a requirement for trusts to carry out the surveys, but no requirement to put the results to work for quality improvement.
- 4.10 The Picker Institute, in its role as a survey provider, offers a package to trusts which includes a bespoke service to help the trust use the results to involve patients in developing an Action Plan for quality improvement. This remains voluntary and is an additional expense for the Trust.
- 4.11 There are some mechanisms in place that are supposed to take advantage of the evidence base. PPI Forums, for instance, are required to monitor the action plans that are supposed to result from Trusts' patient surveys. The extent to which this has been done – and the extent to which trusts respect and enable this role – are uncertain.
- 4.12 There are also departmental standards, on which clinical governance committees are expected to take a lead. These Standards for Better Health (Department for Health 2006) include 'core' (compulsory) and 'developmental' standards, which are in effect good practice guidelines but do not place duties on the committee or the trust.
- 4.13 The 'core' standard that relates to patient involvement states that:
- C17 The views of patients, their carers and others are sought and taken into account in designing, planning, delivering and improving health care services.*
- 4.14 The other key standards relating to patient involvement fall into the 'developmental' category and are as follows:

- D8: *Health care organisations continuously improve the patient experience, based on the feedback of patients, carers and relatives.*
- D9: *Patients, service users and, where appropriate, carers receive timely and suitable information, when they need and want it, on treatment, care, services, prevention and health promotion and are:*
- a) *encouraged to express their preferences*
 - b) *supported to make choices and shared decisions about their own health care.*
- D10: *Patients and service users, particularly those with long-term conditions, are helped to contribute to planning of their care and are provided with opportunities and resources to develop competence in self-care.*
- 4.15 The 'developmental standards' are those to which trusts should be 'progressing'. The Healthcare Commission states that it will begin assessing such progress within its 'annual health check' programme; but in 2006-07 this will not include standards 8-10⁶.
- 4.16 If a 'patient-led NHS' is really the priority which the government says it is, then we must move more quickly beyond this situation, to create more leverage for the active use of the evidence from patient feedback. Some combination of additional regulatory requirements, clinical governance duties, performance management and inspection measures, and/or other incentives may be needed.
- 4.17 The Picker Institute therefore urges the Select Committee:
- **to examine the potential roles of regulation, inspection and other interventions to require trusts to demonstrate that they are involving patients in using their survey results to set priorities for quality improvement**
and
 - **to consider whether the Local Government and Public Involvement in Health Bill should be amended to enable the Secretary of State to impose such a duty on trusts.**

Using the Evidence base (2)

- 4.18 The Picker Institute suggests above that the purpose of patient involvement should be improving the effectiveness of care and treatment through transforming the interaction between patients and health professionals.
- 4.18 The second use to which the evidence base should be put, therefore, is to challenge and confront outdated medical professionalism and organisation. In the NHS Plan in 2000, the government seemed to recognise the core of the problem:

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<http://www.healthcarecommission.org.uk/serviceproviderinformation/annualhealthcheck/howitworks/developmentalstandards.cfm>

"The relationship between patient and service is too hierarchical and paternalistic. It reflects the values of 1940s public services."

- 4.20 There have been some important initiatives since then, such as more emphasis on patient choice, but this kind of reform is often resisted by health professionals. There is little evidence that these outdated attitudes have changed, and they remain an obstacle preventing patients from playing the active role that most say they want to play. Moving forward must involve engaging clinicians as well as patients, challenging them, and encouraging them, to see patients as their partners in the process of treatment and care, not simply as passive victims of ill health. The government and the health service senior management will need to be bolder in challenging the medical professions to modernise their training, education and performance measurement.
- 4.21 Clinicians will need a new set of skills and competencies that barely feature in current training. These will include how to develop the health literacy of their patients; how to enable shared decision making; and how to support patients' self-care. All of these require excellent communication skills.
- 4.22 From their side of the partnership clinicians will need to:
- guide patients to appropriate and personalised sources of information on health and health care
 - educate patients on how to protect their health and to prevent the occurrence or recurrence of disease
 - elicit, listen to and understand patients' preferences
 - communicate clear information on risk and probability
 - share treatment decisions and respect patients' part in those decisions
 - provide support for self-care and self-management.
- 4.23 Some new building blocks are being put in place within the NHS to support this culture change. For example, work is proceeding on the idea of providing an 'information prescription' to patients; and on a 'kitemark' accreditation scheme for information providers. But the culture change itself has to come through the professions. This will require a concerted campaign to persuade the health professions of the need for culture change, based on the mass of feedback evidence that is now available from patients.

'Good Medical Practice': progress, but more needed

- 4.24 A positive recent development is the revision of the General Medical Council's '*Good Medical Practice*', effective from 13 November 2006. This now states that among 'the duties of a doctor registered with the GMC' is to '*Work in partnership with patients*', which means:
- listen to patients and respond to their concerns and preferences
 - give patients the information they want or need in a way they can understand
 - respect patients' right to reach decisions with you about their treatment and care
 - support patients in caring for themselves to improve and maintain their health.

- 4.25 But '*Good Medical Practice*' is, again, a set of guidelines. These will only be effective in creating change if there is continued momentum, from the GMC, through the Postgraduate Medical Education and Training Board, the Royal Colleges and deaneries, and from management throughout the NHS, to provide doctors with the training, the formal requirements, and the incentives that will encourage them to uphold these standards. The Picker Institute is working with the GMC and others to help create such momentum, based on a research programme which has been looking at effective ways to measure performance and for patients to give feedback on their clinicians.
- 4.26 The Picker Institute urges the Select Committee:
- **formally to welcome the new approach to patient/professional partnerships encoded in '*Good Medical Practice*'**
 - **to examine ways in which the momentum for this partnership approach can be pursued, especially through training and through continuing professional development, to ensure doctors uphold the *Good Medical Practice* standards.**
- 4.27 At the same time it must be recognised that the GMC covers only one part of the health workforce. The Picker Institute therefore urges the Select Committee:
- **to recommend to the government that similar processes of revision should be forcefully pursued through the other health professions**
and
 - **likewise to recommend to those professions that they adopt approaches to patient/professional partnership that reflect the *Good Medical Practice* revision.**

Additional needs for evidence

- 4.29 While the value of the national patient survey is emphasized throughout this memorandum, it cannot meet all needs for patient feedback. In particular, the surveys are carried out at an organisational level (by trusts) and therefore do not produce results at the level of the clinical team or the individual clinician. There is a need to discover what mechanisms can work at these levels and to integrate them into performance measurement.
- 4.30 The Picker Institute is currently running the '*Patient Centred Professionalism*' project which aims to:
- learn more about what patients and the public expect of doctors, their professional standards and how these are regulated, and where the obstacles to culture change might lie
 - disseminate these research results to inform and influence principles and, most importantly, attitudes and practice
 - share experiences and ideas of good practice widely amongst an international network of partners.

4.31 One aspect of the research has been to review all the available models, from several countries, of questionnaires that enable patients to comment upon clinicians' performance⁷. This review identified the best models, but still found them wanting with regard to some aspects of care that are important to patients. It therefore recommended that:

- questionnaires more attuned to the patient-engagement agendas of today are developed and include a fuller range of questions
- further consideration is given to the development of questionnaires targeted to specific types of condition or specialty as well as those designed to be administered across a broad range of settings.

4.32 The Picker Institute would therefore request the Select Committee:

- **to recommend to the government and to the relevant health professions that there is a priority need to conduct further research to develop up to date and effective models for patient feedback questionnaires relating to professional performance**
and
- **to recommend to the government and relevant health professionals that these feedback mechanisms be built into the current and forthcoming revisions to professional appraisal and revalidation systems.**

5. How should LINKs be designed?

Use of the evidence base (3)

- 5.1 The change in professional culture described above will be greatly facilitated if other parties within the health system are pushing for the patient/professional partnership approach.
- 5.2 It is here that the LINKs can potentially help to exert pressure for improvement. It should be a central part of their role to receive and understand relevant data from the patient surveys, and to act as advocates for the creation of action plans for change – including organisational change to the way services are delivered, cultural change to the practice of the health professionals involved, and action planning for quality improvement.
- 5.3 The Picker Institute welcomes the new proposals for LINKs. We agree with the LMCA that it is desirable for these to cover both social care and health, to relate to geographical areas rather than specific institutions, and to work closely with the commissioners of health care.
- 5.4 The Picker Institute is concerned that LINKs may struggle to clarify and establish their roles. This is a particular danger with regard to the gathering, analysis and

⁷ 'What do you think of your doctor?', Alison Chisholm and Janet Askham, Picker Institute Europe, 2006

use of information and intelligence on what patients and the public want. Making effective use of such resources is challenging for small organizations, and especially for lay people. But the problems will be greatly exacerbated if government guidance and regulation does not clearly point the way.

- 5.5 The government's most recent explanation of what LINKs should and can be doing places considerable emphasis on the gathering of intelligence and feedback from patients⁸. For example:

*"LINKs will therefore be engaged in monitoring by actively seeking views directly through contributions from individuals and groups, and indirectly from representatives or advocates, from complaints and PALs, through surveys, through comment cards, through websites, and through other methods. Their strength will be that they are able to engage with a large number of people rather than relying on the experiences of a few centrally appointed members."*⁹

- 5.6 Surprisingly, the national patient survey programme is not mentioned once in this document. There is no reference to the existing evidence base. There is no suggestion that there should be a responsibility for trusts to publish and share this information with relevant LINKs in their user area; let alone a requirement for commissioners and providers to involve LINKs in the planning and design of future surveys.
- 5.7 As a result there is a real and present danger that LINKs will waste time, energy and resources duplicating the evidence, reinventing the wheel of survey techniques, or worst of all, struggling with poorer quality evidence when a high quality, properly validated evidence base already exists and continues to develop.
- 5.8 This can be remedied. Section 155 of the Local Government and Public Involvement in Health Bill enables the Secretary of State by regulations to impose duties on a service provider to respond to information requests from LINKs. With slight amendment this Section, and the subsequent regulations, could remedy the omissions.
- 5.9 The Picker Institute therefore urges the Select Committee:
- **to recommend to the Secretary of State the amendment of Section 155 of the Local Government and Public Involvement in Health Bill so as to include a power for the Secretary of State to impose duties:**
 - to publish and share promptly with relevant LINKs information from patient surveys
 - to assist LINKs to analyse and understand the data
 - to involve LINKs in the design and commissioning of future patient surveys.

⁸ 'Government response to A Stronger Local Voice', Department of Health, December 2006

⁹ Ibid, paragraph 1.43

5.10 The Picker Institute agrees with the LMCA and the Patients Forum that there should be an appropriate and effective national presence for public and patient involvement, driven by the voluntary sector, into which the LINKs could feed.

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