GOOD PRACTICE GUIDE
in Programme Management
Foreword

This ERA-AGE Guide to Good Practice is intended primarily for those engaged in different aspects of research programme management. It does not claim to be definitive but, on the contrary, it is offered as a working document that can be augmented and improved as new information comes to light. Indeed readers of this document are actively invited to contribute new information to it and, especially, examples of good practice. This can be done by contacting ERA-AGE, Rita Saddler email r.n.saddler@sheffield.ac.uk.

This guide was generated using information provided mainly by the ERA-AGE partners and the research programmes they sponsor (a full list of the organisations and programmes involved can be found in Appendix 2). ERA-AGE comprises all extant ageing research programmes in Europe therefore this guide does not contain any information on programmes in other regions of the world.

All of the coordination team of ERA-AGE were involved in the production of this guide with Dr Joe Cook, Dr Lubica Strakova and Dr Sam Taylor each playing leading roles during different stages of development.

Alan Walker
Director
ERA-AGE
Acknowledgements

Thank you goes to the following people who have contributed toward the development of this Good Practice Guide.

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1.1 ABOUT ERA-AGE

ERA-AGE is a European Sixth Framework Programme project which seeks to coordinate national research programmes and encourage networking to enable Europe to gain maximum added value from the huge national investments in the field of population ageing research. ERA-AGE focuses on the coordination of national research programmes and related activities and the development of new interdisciplinary programmes based on partnership between countries. In addition, ERA-AGE seeks to promote the development of a European strategy for ageing research. The ERA-AGE partners are united, among other things, in their belief in the need for long term funding for ageing research in Europe.

ERA-AGE has five specific objectives:
1. To facilitate joint interdisciplinary research activities between countries etc.
2. To promote joint interdisciplinary research activities between countries
3. To share good practice in the coordination and management of national ageing research programmes
4. To support the production of European priorities for ageing research programmes and ensure that these are fed systematically into national / regional funding mechanisms
5. To help to break down the barriers between ageing research programmes and policy and practice so that the societal benefits of such research are reaped as rapidly as possible.

In order to achieve these objectives various activities are planned including the development and delivery of three Good Practice workshops and three subsequent Good Practice Guides for research managers.

The first ERA-AGE Good Practice Workshop on Programme Management took place in February 2005 at the Academy of Finland, Helsinki. It brought together the twelve ERA-AGE partners, associate members and other European ageing research funders and policy makers. The focus of the workshop was on information exchange on ageing research programmes and on sharing examples of good practice in programme management. Workshop discussions were informed by data gathered by National Coordinators prior to the meeting. The outcomes of the workshop form the basis of this Good Practice Guide for Programme Management.

1.2 HOW TO USE THE GOOD PRACTICE GUIDE

There are a total of 8 sections in this guide which address various aspects of programme management. Each section has headings and subheadings for ease of reading. There are three general themes in each section which include an introduction to the subject area, standard generally agreed principles, and examples of good practices.
Each section heading is colour coded and towards the bottom of associated pages you will find a matching colour coded box. The contents page has page numbers which also facilitates readers to obtain specific information rather than reading the whole guide.

Examples of good practices are highlighted in blue. The contact details of good practice contributors are available in Appendix 2.

This is intended as an open guide for research managers therefore if you have suggestions for changes or additions of new examples please contact Rita Saddler on r.n.saddler@sheffield.ac.uk
2.1 HOW DO WE DEFINE A RESEARCH PROGRAMME?

A research programme is usually composed of a number of research projects which are focused on a defined subject area or set of issues, scheduled to run for a set period of time and that have some degree of coordinated management. Research programmes usually include a call for proposals which is announced publicly and may be open to all or restricted to certain disciplines or groups. The funding of proposals is usually based on competition.

A research programme is an important tool for the development of research, science policy, research funding and cooperation among different actors in its specific field. Research programmes have both general scientific and policy objectives and more specific goals that are unique to each programme.

A research programme is expected to meet general requirements. It should:

- have a well defined focus,
- be sufficiently broad, and
- have a long enough life span to meet its aims.

A research programme should provide added value in comparison to individual projects. Research programmes differ from each other in terms of their starting-points, objectives and methods.

The usual life cycle of a programme is as follows:

- Preparation
- Commissioning
- Operation
- Outcomes
  - science/knowledge base
  - policy proposals
  - practice based solutions
- Evaluation

2.2 STANDARD AND GENERALLY AGREED PRACTICES

Even though there are differences between research programmes standard common practices can still be identified for example in preparation, commissioning and operation.
2.2.1 Monitoring progress

A useful way of monitoring the progress of projects is to endorse the development of regular written progress reports. The frequency of reports varies among research programmes but generally once a year is seen as sufficient although interim reports may be required depending on the length of the programme.

In many programmes it is common practice for project leaders to write annual progress reports about ongoing activities and interim results of the projects. See for example, The Finnish Research Programme on Ageing, the UK GO Programme, the Dutch Successful Ageing Programme, the Italian Ministry of Health’s targeted research programme-'ricerca finalizzata' and the Italian Ministry for Education Universities and Research targeted programme on ageing-'progetto finalizzato invecchiamento'.

The Processes of Ageing Programme in Luxembourg organises project follow-up on the basis of intermediary reports which are submitted on an annual basis. They are checked by various bodies including the scientific council for scientific content and by the secretariat and the board of administrators for advance payments and budget review reports.

In addition to annual and interim progress reports, Germany’s Health Research Programme of the BMBF host status seminars, network meetings or workshops that are attended by scientific officers from funding agencies.

Benefits to using this approach include:

- It enables programme managers to obtain feedback on progress of projects
- It helps to highlight opportunities especially in regard to initial reports on findings
- It ensures that any difficulties are dealt with as early as possible.

A challenge and limitation of this approach:

- This process takes time and needs to be built into the work plans of projects.

2.3 GOOD PRACTICES

In addition to standard widely used practices there are exceptional good practices that may be useful to consider when developing research programmes on ageing.

2.3.1 Programme steering group

Many of research programmes are monitored by a board of experts who are often referred to as a programme steering or advisory committee / group.

In the UK a majority of the programmes (GO, NDA, ERA, Older People’s Programme) have a steering or an advisory committee. All the programmes funded by the Academy of Finland have a steering committee during the whole cycle of the programme.
In Italy, most programmes funded at a national level are monitored by the National Commission of Health Research (Commissione Nazionale per la Ricerca Sanitaria-CNRS). The targeted programme on ageing-progetto finalizzato invecchiamento, funded by the Italian Ministry for Education Universities and Research (MIUR) and implemented by National Research Council (CNR), was monitored by a board of experts who were members of a Steering Committee (19 members) and a Users Platform (14 members). The board was representative of a broad user/ageing community and organisations who have a general interest in the field of ageing.

**What is the role of the steering / advisory committee?**

A steering or an advisory committee is set up in order to support the director during the life span of the programme. The steering/advisory committee usually comprises some members of the commissioning panel and additional experts, for example scientists and representatives of the broad user community. The committee usually functions throughout the duration of the programme and usually meets twice a year. (The frequency of meetings depends on necessity). Although committee members do not usually play a role in setting up the initiative, they are involved in finalising the programme memorandum and launching a funding call. They also play active roles during the operation of the programme once the initiative has been agreed.

In FNR (Processes of Ageing Programme) an expert group is designated by the scientific council to define the content, duration and budget of the programme. This group comprises researchers as well as potential users (representatives from administration, industry, social groups). The first programme draft is sent for comment to potential users. After the integration of changes, the scientific council comments on the programme and makes suggestions for funding to the board of administration who then submits the programme to the government for funding. The government makes the final decision about programme funding. The programme steering committee is mainly composed of international experts. It meets every 18-24 months and is also responsible for the mid-term and final evaluation.

In Finland, all programmes administered by the Academy of Finland and all programmes administered by ZonMw, the Netherlands, have a steering committee that finalises the programme memorandum which defines the content and aims of the programme.

**What are the main responsibilities of the programme steering/advisory committee?**

- To monitor the progress of the programme and to outline the evaluation procedure
- To support programme coordination
- To carry out other duties related to the programme during the execution of the programme.

Benefits to using this approach include:

- It brings an independent perspective to the operation of the programme
- The committee advises the director when controversial issues arise
- It provides general support to the director or programme officer.
A challenge and limitation of this approach:

- Research programme management is to motivate committee members to play an active role in supporting and following up the programme, while also showing them how their recommendations have shaped the programme.

2.3.2 Calls for proposals

There can be one or several funding calls for proposals in a research programme, each call can have one or more stages. The number of calls depends on the nature and length of the programme.

Some programmes, for example the Academy of Finland and the ESRC GO Programme in the UK, the Italian ‘targeted research-ricerca finalizzata’ and “the targeted programme on ageing – ‘progetto finalizzato invecchiamento’ programmes have only one call when the programme starts and in principle no additional calls are arranged later. However, calls for proposals in other programmes may vary from one call to several calls.

A call is usually publicly announced. It can be open to everybody or restricted to certain groups. All fields of research may apply or it can be restricted to particular fields or disciplines. Eligibility criterion is made available to the public.

At the Academy of Finland, FAS and the UK research councils, a call for a research programme is publicly announced and open to all researchers within the targeted research fields.

At ZonMw, the Netherlands, the programme content and aims determine whether a call is open or restricted.

In Italy, the targeted research-ricerca finalizzata programme calls are open to any researchers but only in eligible institutions.

a) One-stage call and two-stage calls

It is debatable which is more effective: a full proposal in one stage or two-stages consisting of a brief proposal and then a full application. The decision about how many stages the call should have depends on the size of the budget.

At FAS, in Sweden, a two-step approach to grant applications has proved to be beneficial. Firstly a brief outline is submitted to the council and, if approved, a full application is submitted at a second stage. The system has not been evaluated but it is generally appreciated by researchers as it saves them time and effort.

The ESRC, in the UK, routinely uses two stages. The first stage involves a request for outline proposals. A commissioning panel assesses outline proposals and establishes a short-list of successful applications to go forward to the second stage. Successful first stage applicants are then invited to submit full proposals which are submitted for scientific peer review.
The UK NDA Programme employed a novel two-stage approach by calling for proposals for up to 12 months funding to enable the development of innovatory collaborative research project applications.

Benefits of using a two stage approach include:

- Two stages are useful when a large number of proposals are expected.

Challenges and limitations of a two-stage approach include:

- It takes much time and resources
- A longer processing period is required
- Large numbers of outlines (100-150) covering a broad spectrum of research topics may be dealt with by a limited number of committee members
- Reviewers may confront a very high workload. All applications in both stages are reviewed objectively and professionally by external reviewers when possible. This may generate a high workload for reviewers.
- Applicants may be discouraged if the chances of securing funding is relatively small.

b) Peer review of applications

It is recommended that all applications are reviewed by external experts and where possible by international reviewers. The establishment of a peer review committee, whose purpose is to select proposals and assist in identifying external reviewers, is also recommended. Review committees rate and rank proposals based on evaluations previously undertaken by external reviewers. Alternatively panels of experts undertake both the evaluation, rating and ranking for the decision making body.

At the Academy of Finland, FAS, ZonMw and in the UK GO, NDA and OPUS Programmes, applications are scientifically peer reviewed by external experts and panels.

At the Academy of Finland peer review of applications is carried out mainly by international panels of experts. The expert panel prepare a joint statement on each application based on draft reviews written by panel members. The programme manager and scientific advisor, who are responsible for the research programme, organise the evaluation process.

In Italy, for example, peer review is undertaken by the National Commission of Health Research (Commissione Nazionale per la Ricerca Sanitaria) for the targeted research programme. The review panel comprises the President (Minister of Health, Vice President and external national experts including representatives of the main (public and private) scientific research institutions, regional, Ministry for Education Universities and Research and Ministry of Health.
The Israel Science Foundation (ISF) maintain over 55-60 revolving Professional Committees involving professionals in the fields of Exact Sciences and Technology, Life sciences and Medicine, Humanities and Social Sciences.

The Foundation’s Information specialists organise suitable reviewers via email. Reviewers are assigned a number and pin number which enables them to review proposals on the Foundation’s website and subsequently forward their evaluations. Specialised external peer review is combined with discussion by broader committees to ensure comprehensive evaluation.

Anonymous feedback should be given to applicants. Some funders such as ZonMw operate a rebuttle system where applicants are given a chance to appeal and resubmit their applications. During the first round of the UK NDA Programme, applicants were able to respond to peer reviewers’ comments.

Anonymous feedback is given to all applicants who apply for grants from the Italian Ministry of Health’s targeted research programme. Applicants are able to appeal and resubmit their applications. Since 2006 feedback has been provided in English to accommodate recent involvement of international referees.

It is advisable to use standardised peer review forms and ensure that reviewers support their conclusions in writing. International review panels usually provide feedback in English which is advantageous for reviewers and applicants.

In the UK GO, OPUS and EQUAL programmes and at the Academy of Finland and Luxembourg’s FNR, detailed and anonymous feedback on proposals is given to all applicants. Reviews conducted by FNR include comments relating to the selection criteria. Applicants receive project evaluation feedback together with anonymous expert comments.

Benefits to using this approach include:

- It enables proposals to be judged on the basis of advice provided by other scientific experts in the field
- Peer review committee/panels ensure that proposals are reviewed together by external experts in an open discussion where various points can be raised and discussed in a transparent process and a decision can be reached quickly
- The rebuttle system is highly appreciated by the scientific community who sometimes perceive the review process as fairer.

A major challenge to this approach concerns:

- Difficulties in identifying and engaging high level experts
c) **Using standardised review forms**

Many programmes use standardised review forms which may include written evaluation and scoring (using a scale from one to five).

The Finnish Research Programme on Ageing 2000–2002 involved an Expert Panel consisting of nine foreign experts from different fields of ageing research who reviewed proposals using standardised review forms with the following criteria: scientific quality, originality, innovativeness, relevance, scientific competence of the applicant, organisation and co-operation and a scoring scale from one to five.

It is advisable to use a standardised evaluation form for all applications which should be made publicly available (on the website) to guarantee transparency.

All reviews should be sent to applicants anonymously. Feedback should include comments but scores in the feedback are not recommended. Reviews should be anonymous unless there are legal restrictions in which case anonymity is not possible (For example in the Netherlands the juridical systems does not allow anonymous feedback). Rebuttle procedures should be used whenever possible.

Results of evaluations and the evaluation criteria should be made available to evaluators and applicants. If there is a possible conflict of interest, all controversial issues should be resolved in advance. It is preferable to use a panel of external experts.

The Academy of Finland’s peer review process is designed to ensure transparency, open discussion by the panel, written concise statements (reviews) and disclosure of conflict of interest issues.

Benefits to using this approach include:

- Standardised procedures ensure uniform assessment of applications
- The process facilitates reviewers
- Assessments are made clear and comparable for applicants
- All documents are, or should be, open to public scrutiny to guarantee the objectivity and transparency.

**d) Separation of scientific reviewing from decision making to guarantee that both the scientific quality and policy strategies are to be taken into account**

It is advisable to separate evaluation and decision making processes. The panel should evaluate applications on the basis of their scientific value and the funding agency should determine how to distribute funds. Funding agencies should provide reasons for changing rankings and thereby overwriting scientific assessments/decisions. During the review process, applications should be reviewed on the basis that there are sufficient resources to fund all. It is recommended to use different criteria for newly established researchers or less supported areas of research in order to support researchers and less established fields/areas of research and researchers.
At the Academy of Finland (for the Finnish Research Programme on Ageing), the programme steering group establish a list of applications to be funded which is subsequently submitted to the sub-committee for final funding decisions. The list is based on scientific evaluations undertaken by panels, relevance of projects to the programme and the science policy strategies of the Academy of Finland and other funding agencies. The subcommittee decides which projects are funded by the Academy.

In Germany’s Health Research Programme of the BMBF, scientific review is undertaken by experts in the field and associated administration is coordinated by the programme manager and scientific officers in the project management organization (“Projektträger” PT-DLR). The Federal Ministry makes the final decision.

Benefit of this approach:

- Transparency through separation of decision-making and reviewing processes.

In contrast, FAS in Sweden operates a system whereby the same members of the board are involved in reviewing research grants and in decision making to approve grant applications. Members of the board are very familiar with, and engaged in, the process of granting research support at FAS and they have good insight to decisions made by the board. However, there are some limitations to this successful approach because the same people are involved throughout the process.

e) **Coordination or interaction between projects, through workshops and meetings and having a separate budget for coordination**

Many research programmes develop strategies to enable projects to work together, to engage in joint learning and dissemination and thereby develop a coordinated approach to the research being undertaken by the programme.

In France the CNAV and the MiRe, the programme on Ageing and Technologies established a permanent process of exchange. Seminars were held twice a year with all participating teams in the programme which enabled information exchange on projects progress. As a result, difficulties could be identified and improvements made. In addition experts, from outside the programme, were invited to one day workshops. Two important seminars were held at the Ministry of Research and the CNAV where projects presented their findings to representatives from other institutions and user groups (older people, private and public institutions, business groups). These seminars gave rise to reports which were then circulated to interested parties.

Coordination and interaction between projects is best carried out through workshops and meetings. The level of coordination depends on the goal of the programme. It is essential to have organised contacts between the coordinator and projects and between different projects. Coordination should be an integral part of programmes if it helps to achieve programme’ goals.
In the UK the GO and other research council programmes organised research days for project teams that involved individual studies to identify common themes and issues while encouraging a sense of working as a team. Site visits were also used to stimulate links between projects. Programme meetings were one of the networking mechanisms, sub-groups on specific themes such as ethnicity were also established. In addition, the OPUS programme ran occasional seminars for Department of Health officials, designed to keep policy makers engaged in the ongoing progress of research.

ZonMw, the Netherlands, organise project leaders meetings with the aim of encouraging networking.

In Italy, the Ministry of Health endorses interaction between projects in the targeted research programme. A separate budget is provided to support coordination and communication between projects through events such as seminars, meetings, workshops.

A separate budget for coordination is necessity in order to achieve added value from the programme. It should include programme management, coordination activities, communication approaches, seminars, meetings, workshops, etc. The separate budget should consider and cater for special tasks or goals such as, for example, the promotion of interdisciplinarity. The scope of the budget depends on the type of programme.

The GO Programme had a separate budget for coordination (including technical support, communication, seminars, international activities). While this budget was still restricted it enabled the buying out of the Directors time and the hiring of administrative staff.

Whereas in Finland problems were encountered due to a lack of a separate budget and workloads varied during the course of the programme.

The lack of technical support was a main concern resulting in wide ranging tasks undertaken by the coordinator from science policy issues and content of the programme to copying and mailing. The coordinator should be supported by secretarial and technical staff.

Benefits to using this approach include:

- A separate budget for Coordination facilitates the smooth running of programmes although the scope of the budgets largely depends on programmes’ goals
- Researchers are given the opportunity to keep in touch with the needs of users and their counterparts which enables them to learn from each other
- Added value can sometimes be generated from projects.
A challenge and limitation of this approach:

- In some cases programme management has been regarded as insufficiently active; funding opportunities for accompanying measures, regular activities to stimulate exchange between projects lacked systematic organisation with the exception of steering committee meetings.

f) **Grants for post doctorate and newly established researchers**

Grants for post doctorate or newly established investigators are desirable because they help to attract and retain new talent to the research field. Careful consideration should be given to funding approaches such as direct funding for post doctorate or newly established researchers or indirect funding by encouraging individual projects to recruit them. Research training and career development of post doctorate and newly established researchers should be supported by individual programmes to assist them in establishing their career in the ageing field. Support in the form of paid positions for post-docs and/or training courses should be made available. It is essential to build a community through joint training programmes. Methods and practices may vary between programmes.

At ZonMw, the funding opportunities for newly established researchers and post-docs as well as small grants and network grants (consortia) proved to be beneficial.

FAS organises contacts and networks between researchers from the same field. This is generally carried out through conferences and by providing special grants for the creation of networks between researchers in the same area. The latter is considered as good practice and worthy of replication in other countries. By stipulating this specific aim, funders are assured that networking is achieved and subsequently reported in the final report.

In Israel, the Ministry of Health has a scheme for encouraging newly established researchers in peripheral hospitals.

The Italian Ministry for Education Universities and Research “targeted programme on ageing – ‘progetto finalizzato invecchiamento’ programme was unable to provide direct funding for PhDs and scholarships. However, newly established researchers obtained scholarships which were funded by external sources such as pharmaceutical industries.

Benefits to using this approach include:

- It facilitates the entrance of post doctorate and newly established researchers into the scientific community
- It can be used as a tool to mainstream ageing research
- Through joint training programmes, young researchers from different backgrounds and research disciplines can be linked with the scientific community and establish their career
- It may prevent the exit of post doctorate and newly established researchers and the associated loss of their skills.
PROGRAMME EVALUATION

3.1 WHAT IS PROGRAMME EVALUATION?

Programme evaluation is a systematic (and as objective as possible) examination of a planned, ongoing or completed programme. It aims to answer specific management questions, judge the overall value of an endeavor and identify lessons learned to improve future actions, planning and decision-making.

An evaluation should provide information that is credible and useful, offering concrete lessons to help partners and funding agencies make decisions. A programme-level evaluation provides a detailed analysis of the strengths and weaknesses of a programme, and helps to determine the impact and value of the investment.

3.1.1 Why do we evaluate?

We evaluate in order to know what steps to take next or to find out if a new type of research could emerge from the previous one. It is important to clearly articulate the purpose of evaluation and it is advisable to know beforehand if the aim of the evaluation is to obtain more money or to encourage a new type of research. Evaluation provides a basis for accountability, as well as useful information for the public.

3.1.2 What are the differences between an interim evaluation, final evaluation and self-evaluation?

- **An interim evaluation** is carried out when the programme is still running. Countries which have continuous programmes usually conduct an interim evaluation during the lifespan of the programme to monitor progress
- **A final evaluation** takes place when the funding period has ended
- **Self-evaluation** is conducted in-house, usually within the funding agency or research institution. The internal or self evaluation is usually conducted by a grant providing organisation/funding agency and does not need to be as extensive as the external evaluation.

Research programmes are evaluated in relation to the starting points of the programme, its objectives and scope of funding. The stages of the evaluation include:

- definition of objectives
- planning and budgeting
- carrying out the evaluation
- reporting
- utilisation of evaluation results.
It is important to note that evaluation requires time, money, resources and planning. Evaluation can be conducted by a private or public sector organisation, funding agency or a ministry.

Below are some examples of standard and good practices that may be useful and worthy for replication.

### 3.2 STANDARD AND GENERALLY AGREED PRACTICES

Evaluation is a widely used practice across ageing research programmes. However, not all programmes carry out an evaluation and differences exist in regard to the frequency and methods of evaluation. Programmes are often evaluated during their life span and/or or when the funding period has ended.

#### 3.2.1 Carrying out an evaluation (interim and/or final) at the programme level and planning sufficient budgets for evaluation

The use of interim and/or final evaluation processes are widely accepted practices in ageing research programmes.

- The aim(s) and criteria of an evaluation need to be clarified and tailored to the purpose of the evaluation
- The programme should be evaluated as a whole and the identified aim of the evaluation should determine the structure of the evaluation criteria
- The main evaluation criteria should be made known to researchers upon commencement of their programme
- Important evaluation criteria are:
  - accountability
  - effectiveness.

The following issues should be considered when planning an evaluation:

- Consider the timing of evaluation carefully. Only parts of the scientific outcomes of the programme (e.g. peer reviewed publications, dissertations, parents etc.) are available when the programme funding ends. It is important that a realistic time span is provided if the impact (social relevance) of the programme is to be evaluated
- Plan a sufficient and realistic budget when setting up the initiative. Large and long term programmes should have a sufficient budget planned for this purpose
- Consider who the evaluators should be (for example external and/or international). Again large and long term programmes should use external reviewers and publish extensive reports to maximise the impact
- Identify resources required for the evaluation being undertaken. Resources should also be allocated to the organisation of a closing programme seminar which enables researchers to present their work
- Consider payment for reviewers. Members of expert panels may be paid an honorarium in addition to their expenses
- Invest money in the process of evaluation so future improvements can be made.
Below are some examples of evaluation models used as standard practices across ageing research programmes.

Austria (IBA, VID, ZENTAS), Ludwig Boltzmann Institutes and France (Ageing in the Workplace) have continuous programmes and conduct interim evaluations.

The Academy of Finland (Finnish Programme on Ageing), the Romanian VIASAN programme, the FAS ageing programmes and the UK (ERA, GO, Older People’s Programme) have conducted and/or are currently conducting final evaluations.

FNR, Luxemburg (Processes of Ageing), ZonMw and the Italian Ministry of Health’s targeted research programmes endorse a model involving both interim and final evaluations.

The majority of programmes across the ERA-AGE countries, except Austria and Luxembourg, carry out self-evaluation in addition to final and/or interim evaluations.

A particularly interesting example of a special form of evaluation has been provided by the UK Older People’s Programme where the ‘evaluation’ comprise older people’s views of the saliency of the findings. Ideas have been tested within individual projects, with the Older People’s Steering Group and with older people at the programme launch.

Benefits to using this approach include:

- Evaluations help to identify what steps to take next and/or new research that may emerge from the programme
- Internal evaluations may be less extensive as external evaluations
- Internal or self evaluation may be carried out by the funding body.

3.2.2 Using external experts

External experts are those who are not employed by any funder of the programme or members of boards responsible for organising programme funding. Independent experts should not be members of a programme’s steering committee or scientific advisory panel. A programme’s final evaluation (and in some cases the interim evaluation) should be carried out by external independent domestic or international experts. Evaluators may include older lay people themselves.

The UK Older People’s Programme was, for example, evaluated by older people themselves.

The Academy of Finland and FAS in Sweden commission international expert panels.

At ZonMw (the Netherlands) and within the Italian Ministry of Health’s targeted research programme final evaluations are carried out mainly by domestic external evaluation committees.
At FNR, Luxembourg the standard practice is to use a steering committee of international experts which conducts the interim evaluation of the programme every 18-24 months.

In the UK (GO Programme), the ESRC evaluation unit commissioned a single independent expert to carry out the final evaluation.

When carrying out an evaluation various approaches may be used:

- Experts may receive written documentation on all the projects
- Project exhibitions of work undertaken may provide the part focus of evaluations
- Project leaders may give presentations of their work
- Researchers may attend meetings with evaluation panels who may ask questions face to face and enable researchers to obtain first hand feedback from esteemed peers
- Multidisciplinary ageing research centres may be visited as part of the evaluation.

Benefits to using this approach include:

- Transparency
- Objectivity – large programmes should especially use independent experts which is a requirement and this requirement by some funding agencies
- Impartiality in regard to the final evaluation
- Facilitating and desirable in regard to, for example, programmes that are extensive involving undeveloped fields which need to demonstrate new activity.

A challenge and limitation of this approach:

- Careful consideration must be given to the recruitment of experts to the evaluation panel.

### 3.2.3 Making evaluation reports publicly available

Evaluation reports should be made publicly available; actively presented to appropriate public audiences and actively distributed. If possible, a summary of the report should be made available in English or an internationally accessible language. It is standard practice in all the ageing research programmes to produce publicly available documents.

Benefits to using this approach include:

- Maximising the impact of evaluations
- Increasing transparency of funding organisations
- Reinforcing project impact and increasing knowledge sharing.

### 3.3 GOOD PRACTICES

If the aim is to achieve added value from evaluation, some of the following examples of good practices might be worthy of consideration.
3.3.1 Including self-evaluation in the final and interim evaluation at the programme and project level

A self evaluation may be carried out at project/programme level by project leaders and researchers. Self-evaluation at project level best provides an opportunity for learning and developing activities.

The coordinator of the Finnish Research Programme on Ageing compiles a report containing a programme level self-evaluation. The coordinator also evaluates their work.

In the Netherlands at ZonMw’s Successful Ageing programme, the final evaluation contains a self-evaluation carried out by the programme officer. The internal self-evaluation report is subsequently evaluated by an external evaluation committee. Interim evaluations may also include self-evaluation.

Benefits can be gained by using this approach since it provides:

- background material for the evaluation panel
- parts of the report which may be worthy of publication
- an opportunity for learning and developing activities.

3.3.2 Conducting an interim evaluation

The need to carry out an interim evaluation may depend on the length of the programme. It should be as simple as possible and carried out only if it has a further impact on the programme.

A main benefit to using this approach:

- Interim evaluations are worthwhile when there is a possibility of improvement to programmes or projects can be adjusted.

An interesting example is provided by CNAV, France, where interim evaluations of the continuous programme ‘Ageing in the workplace’ have resulted in modifications in research practices, in the orientation of recruitment and in the coordination of a disseminated collective.
4.1 WHAT IS DISSEMINATION?

Dissemination processes can vary between ageing research programmes but all programmes develop strategies for getting their results out into the public domain. Three levels of knowledge dispersal can be identified:

- **Communication** – usually takes place in the early stages of a programme and project development involving the distribution of information concerning programme objectives and research being undertaken
- **Dissemination** - takes place once research results begin to emerge. Dissemination may involve different approaches to sharing knowledge from standard publication of journal articles and conference papers to non-standard forms such the running of public access workshops, user or policy targeted publications
- **Implementation** – only takes place once the research is complete and the product/model is clearly developed. Implementation ‘involves processes where the results from projects are put into practice in terms of developing policy and outcomes’. This can be facilitated by developing partnerships between the research projects, the programme and policymakers, users, service providers etc, who will work together to implement the product.

4.1.1 Who are you disseminating to?

It is important to be clear about the target audiences or end users when designing a dissemination strategy. A target audience may include, for example:

- Policy makers
- NGOs and lobby groups
- Service providers
- Front line professionals
- The media
- The public
- Other scientists
- Industry

…..and develop your strategy accordingly.

It is also important to bear in mind that programme dissemination and implementation plans need to build in time and resources for activities to have an impact. It is therefore crucial that researchers develop skills necessary to achieve effective implementation of research findings and recommendations. Skills for dissemination are not necessarily the same as those used for research, which in the context of competing pressures on researchers, can pose problems for dissemination. Programmes may offer systems of support that will facilitate projects to disseminate and implement findings into the public domain.
4.2 STANDARD AND GENERALLY AGREED PRACTICES

4.2.1 Programme level dissemination and implementation plans

Ageing research programmes are required to develop a dissemination plan and/or a strategy for implementing results. This ensures that dissemination is developed as an integral part of the programme and that the programme evolves with these objectives in mind. In many cases where dissemination is high on the programme agenda, the links to the policy and user communities as well as services and industry are made from the onset of the programme which increases the connections between science and society.

In the GO and New Dynamics of Ageing Programmes in the UK, and the programmes run by FAS in Sweden and ZonMw in the Netherlands, programme dissemination plans are followed through by requesting information, in calls for project funding, on how results will be disseminated.

4.3 GOOD PRACTICES

While the importance of developing dissemination plans is common across programmes, approaches to achieve this can vary. Some interesting examples of good practices have emerged from the ageing research programmes and are worthy of consideration when developing new programmes.

4.3.1 Requiring specific dissemination and implementation plans

Programmes often require projects to develop specific plans for dissemination and implementation of results.

The dissemination and implementation of results forms a core priority in ZonMw, in the Netherlands, especially targeted is the transfer of knowledge to the general public and policy makers and to try to bring products to the users. For example programmes require all proposals and grant applications to provide information on how they intend to achieve knowledge transfer and implementation. During the whole programme attention is paid to implementation and it is facilitated by collaboration between researchers and workers in practice. Every researcher of the programme is responsible for dissemination of their research results and products. To help researchers with this process, programmes organise meetings to explain essential information about developing dissemination plans.

A similar requirement is adopted by a Romanian research programme funded by the Research Grant System of the MedC.

Benefits to using this approach include:

- Traditional forms of dissemination, for example through journal publication, are standard practice for scientists but they often find it difficult to translate their findings into practice and to get their models and products implemented.
• Research programmes can play an important role in facilitating the development of more extensive research implementation and helping scientists to develop skills to translate their findings into practice
• Researchers are often subject to competing priorities and it may be necessary to require them to write a dissemination and implementation Plan (VIP)
• In the absence of dissemination and implementation plans, important societal values from research may be lost or under developed. The process also ensures that project leaders are more involved with implementation.

In addition to providing training, programmes may help projects to make links with policy makers, professionals etc.

    ZonMw, in the Netherlands, facilitates the link between projects and policy makers where appropriate within programmes.

A challenge and limitation of this approach:

Dissemination processes place additional responsibilities on projects which involves time and resources.

Alternatively:

    In Israel, the dissemination and implementation of most research programmes is undertaken by ESHEL, a non-profit organisation specifically established to work on practical applications of ageing research. ESHEL-NET is a website of the JDC-ESHEL to provide information to professional researchers, academic, lay people, the elderly and their families on JDC-ESHEL’s programmes and services for the elderly throughout Israel.

4.3.2 Providing specific funding for dissemination and implementation

The requirement of projects and programmes to undertake specific dissemination and implementation activities requires the allocation of an appropriate budget to be successful.

    In the Netherlands, ZonMw provides additional money for implementation.

    In Italy, the Ministry of Health’s programmes incorporate cost plans for dissemination of results.

    In the UK dissemination activity is often funded, a sufficient amount of the initial funding allocation is retained by building the costs into the contract with the academic coordinator or by applying for subsequent monies from the PRP budget.

Benefits to using this approach include:

• Securing additional resources for dissemination means that more of the initial allocation can be used to fund direct research activity
• Without effective dissemination to the full range of interested audiences, the value of the public money invested in the research can be lessened
• Funding dissemination separately ensures that projects are able to effectively prioritise dissemination
• Further by separating out this budget and requiring all projects to provide dissemination plans, the risk of projects which prioritise dissemination may be seen as less competitive than those who do not because they cost more, is reduced.

4.3.3 The production of special publications for public consumption

Dissemination of research outcomes and raising the profile of the important role that research plays in society is a major issue that all research funders have to address. One way of addressing these concerns is for programmes to set aside specific budgets for the production of user friendly booklets and summaries of research findings.

In the UK the Growing Older Programme produced a series of popular public documents. All summaries of project results were developed into publicly accessible user-friendly findings reports. Also the programme produced, in partnership with Help the Aged, a summary of the programme results selected by older people and specifically targeted towards this group.

In Austria, the IBA has been co-editing with US partners in regard to the journal ‘Experimental Gerontology’ which is designed specifically to disseminate biogerontological research results to strengthen the field, support networks formations and to speed up translation of basic research results into practical application.

Benefits of using this approach include:

• The profile of the contribution that science makes to society is raised while also disseminating important information to older people, their representatives and other users
• Good opportunities could be lost if research results are not translated into a popular form
• Publications can raise public awareness of what ageing research is about.

4.3.4 Media Training for Scientists and Programme leaders

To ensure successful dissemination it may be important to provide media training for programme managers. This strategy was adopted by the Academy of Finland for its programmes. As part of this process, programmes facilitated contact between its projects and the media, for example by announcing important results and also developing links with the reporters who are relevant to the field of research of the programme and linking these with particular projects. In addition some programmes held regular working breakfasts with representatives from the media.

4.3.5 Programme Workshops

The organisation of symposia or workshops can greatly aid the dissemination of research results. These can be organised along different thematic areas and users, policy makers, service providers etc. can be invited to participate.
In the UK, the EPSRC ran a workshop on assistive technology where one of the speakers spoke about housing design or re-design and how houses can be adapted so older people can stay in their own homes. This was important because there was a technical aspect as well as an economic appraisal to it concerning the amount of money that could be saved by keeping somebody at home rather than in a nursing home. Practitioners at the meeting immediately saw the value of it and they used these findings and presented the savings to their local borough council.

Also in Luxembourg, FNR accompanying measures allow for additional funding to support conferences, publications, international mobility. FNR programmes/projects encourage the promotion of a scientific culture in Luxembourg: head of projects are to an important extent involved in the Science Festival every two years and they actively collaborate in promoting research among young children and students.

PT-DLR in Germany organised the BMBF-workshop for journalists which runs twice a year around selected topics from the Health Research programmes. National conferences are also organised to disseminate research programme findings such as ‘the National Year of Life Sciences’ in 2001 and the ‘National Day of Health Research’.

Benefits of using this approach include:

- Working from the bottom up and using findings that can have a direct effect on policy making and bring real benefits to older people
- Educational activity is an effective way of disseminating research results. Dissemination provides researchers with an opportunity to test the applicability of their findings.

A challenge and limitation of this approach:

- The impact of research relies a great deal upon contact between the researchers and practitioners and so the extent to which research work can be disseminated is fairly limited.

4.3.6 International Dissemination

Programmes can require their projects to produce short English language summaries of their key results to ensure the widest possible dissemination of research results.

This was practiced in Latvia and Romania and was seen as an essential part of enabling international dissemination and research collaboration.

Benefits of using this approach include:

- Important added value can be gained by establishing this good practice
- Opportunities for research comparison and collaboration may result
• Awareness is raised about what research is being undertaken outside of one's own country.

A challenge and limitation of this approach:

• Scientists who do not speak English are at a disadvantage and will need support with translation. Research programmes may need to budget for this.
SECTION 5

MULTIDISCIPLINARY, INTERDISCIPLINARY AND TRANSDISCIPLINARY RESEARCH

5.1 ABOUT MULTIDISCIPLINARY, INTERDISCIPLINARY AND TRANSDISCIPLINARY RESEARCH

5.1.1 Why is Collaboration between Disciplines Important?

Growing older affects all aspects of human life - biological and physiological, psychological, social, economic and environmental. This means that no single discipline has all the answers and the quality of life of older people can only be improved through the accumulation of knowledge from multiple disciplinary perspectives and interdisciplinary learning.

5.1.2 What form does it take?

The collaboration between disciplines may take various forms including:

- **Multidisciplinarity** which is more or less parallel activity of two or more disciplines engaged in one project
- **Interdisciplinarity** where research projects involve more than one disciplinary perspective and seek to integrate these perspectives in the research process. This can be through building an interdisciplinary team or through the development of interdisciplinary researchers
- **Transdisciplinarity** this is often regarded as the highest level of collaboration as it involves the integration of different disciplines' views and methods, giving rise to a completely new integrated approach including the development of new theories or new methods.

5.1.3 How can research programmes encourage interdisciplinary research?

Interdisciplinary research can be encouraged in different ways:

1. Interdisciplinary projects can be specified in funding calls
2. Programmes can be jointly funded by several different research councils
3. Programmes can fund and facilitate interaction and learning between its projects from different disciplines
4. Interdisciplinary research training can be built into programmes.

Apart from collaboration between academic disciplines, interdisciplinarity can also mean collaboration with professionals that are experts in specific ageing–related topics such as nurses or professional care-givers.
5.1.4 What are the benefits of interdisciplinarity?

- Cross disciplinary learning
- Increased and richer understanding of the ageing process, especially quality of life in old age
- Developing an integrated view can help contribute to the overall quality of the research.

5.1.5 What are the obstacles to research programmes developing interdisciplinary collaboration?

All countries have their own unique research cultures and their own specific constraints and opportunities to the building of interdisciplinary research. However some general issues can be identified and are worthy of consideration.

- Separation of research into disciplinary departments can act as a disincentive to interdisciplinary research collaboration
- Lack of rewards, outputs and career structures for interdisciplinary research such as interdisciplinary journals, funding opportunities and job opportunities
- Differences in the scientific paradigms, cultures and languages across the disciplines
- Restrictions in funding structures which is a necessary prerequisite for carrying out research.

Some specific national examples are:

In the UK the periodic Research Assessment Exercise does not take sufficient account of interdisciplinary research and lower research credits due to the multiple disciplinary authorship of publications can be a problem. However this is to some extent offset by the funding agencies encouraging interdisciplinary collaboration.

In Romania, funding for research is limited which discourages funders from awarding funds to other disciplinary fields outside of those traditionally linked to the programme. This is being countered by the development of specific calls for interdisciplinary projects.

Some countries, such as Austria, have had some good experiences in developing interdisciplinary collaboration with research programmes on ageing. This enables interdisciplinary collaboration to be performed over the mid or even long-term which facilitates a form of continuous communication and development that is difficult to achieve through the funding of single projects.

Having reviewed the constraints this guide now focuses upon what is achievable within research programme management by reviewing some useful examples of standard and good practices in this field.
5.2 STANDARD AND GENERALLY AGREED PRACTICES

Multidisciplinarity and interdisciplinarity are standard and generally agreed practices among many ageing research programmes.

Multidisciplinary collaboration on the programme level can involve:

- Regular seminars to encourage networking and strengthen gerontological expertise
- Thematic workshops to facilitate dialogue between disciplines
- Joint cross disciplinary researcher training
- Joint publications and sessions in national and international conferences.

Interdisciplinary programmes are set up to fund interdisciplinary projects that submit commonly presented proposals combining e.g. engineering and social sciences; sociologists and anthropologists; medical and social/behavior sciences and so on. Other interdisciplinary programmes combine basic and clinical sciences. Some programmes also request that projects stipulate their interdisciplinary approach as criteria for funding.

Benefits to using this approach include:

- Due to the multifaceted nature of growing older and its capacity to shape every aspect of human life, no single discipline is capable of addressing the issue of ageing. The only way to develop research that can extend the quality of life of older people is by funding research on ageing in a manner that enables the accumulation of knowledge from multiple disciplinary perspectives and interdisciplinary learning.

The challenges and limitations in developing interdisciplinary and multidisciplinary programmes include:

- Differences in research objectives: ways of defining research objectives differ between disciplines
- Differences in research language: meaningful communication cannot easily be achieved
- Different methodological traditions: for example sociologists are strong in methodology whereas engineers have a different frame of reference
- Dissemination of results and publishing traditions differ between the disciplines
- Domination of one disciplinary perspective over another: in interdisciplinary projects no discipline should dominate the others but there is usually a leading discipline in a project
- Academic credit: interdisciplinary expertise generally attracts low academic credit; resulting articles are difficult to get published in leading disciplinary journals; there is a risk of researchers loosing their expertise in their own discipline and becoming less aware of latest developments; these potential problems may hinder career development especially since there are very few opportunities for interdisciplinary researchers
- Funding: multidisciplinary and interdisciplinary projects have problems with funding, particularly those which cross the border between social and medical sciences
- Peer review: it is difficult to find adequate reviewers for interdisciplinary projects; difficulties are encountered in getting interdisciplinary projects through the peer review process; difficulties arise in regard to reviewing of multidisciplinary and interdisciplinary research plans.
The potential difficulties in interdisciplinary collaboration mean that these projects may need extra time for preparation. It is extremely important to consider necessary resources when developing an inter or multidisciplinary programme.

Resource and organisational issues to consider include:

- In some cases, interdisciplinary collaboration should be preceded by a preparatory phase that should also be funded
- In order to avoid too wide a range of topics the scope of multidisciplinary programmes should be well defined
- Common activities could be organised between small thematic groups
- Specific funding for coordination activities, targeted seminars and workshops could be provided
- Interdisciplinary training activities could be provided
- Regular meetings could be arranged to overcome the language and methodological problems
- A longer term funding perspective needs to be adopted.

5.3 GOOD PRACTICES

There are some important good practices that are worthy of consideration when developing interdisciplinary programmes.

The institutional level:

5.3.1 Interdisciplinarity Performed in Research Institutes

Institutes are a useful way of fostering long-term interdisciplinary research collaboration.

A longer term funding structure and concentration of research disciplines within one institute allow more time for developing interdisciplinary approaches and learning about disciplinary methods, their possibilities and their restrictions.

Examples include:

The Institute of Biomedical Ageing Research (IBA, Austria) facilitates collaboration between basic research, biomedical ageing research and its clinical application by partner institutions. Very specialised forms of collaboration may be developed by increasing knowledge of other disciplines. Sustained forms of interdisciplinary collaboration arise out of the middle-term or long-term perspective that is guaranteed by the institute’s funding structure.

In the Netherlands, interdisciplinary research forms the main goal of the Research Institute of Diseases in the Elderly (RIDE). This institute is set up to stimulate synergy between different disciplines of biomedical research. This is achieved through the use of the same population of elderly people (Rotterdam Study) by all researchers.
Furthermore collaboration between top quality research groups is stimulated by requiring them to write proposals together.

Benefits to using this approach include:

- A longer-term perspective is important since continuous and time-consuming communication is needed in order to achieve good results and this is difficult to reach in the lifetime of a single project
- Continuous contact and collaboration with other disciplines heightens understanding of other methods and difficulties and it can help to generate future transdisciplinarity
- Increased understanding of different disciplines, methods and possibilities enables the development of very specialized forms of collaboration.

A challenge and limitation of using this approach:

Investment of resources in a single site can result in opportunities being closed to other researchers outside the institute, unless the institute operates open calls for projects. Newly established research groups may encounter difficulties in joining larger groups due to lack of experience.

The programme level:

5.3.2 Developing interdisciplinary programmes through funding of individual projects

The core objective of creating and supporting interdisciplinary research is built into interdisciplinary programmes. Interdisciplinarity is a central criterion for attaining project funding and some programmes support the development of interdisciplinary proposals through workshops and regular meetings. Interdisciplinary programmes are able to bring together disciplines that have very different approaches to the issue of ageing research but that need to collaborate to advance knowledge in this field.

Examples include:

In France, the Technological Development and Ageing programme calls for proposals specified interdisciplinarity and it sought to bring together the natural with the social sciences.

The key aim of the Dutch programme ‘Successful Ageing’ is to promote autonomy and independence of older people by stimulating interdisciplinary intervention-research. Not only the researchers but also the instruments used and outcomes achieved, were from a wide range of disciplines (neurology, geriatrics, endocrinology, internal medicine, rehabilitation, psychology and sociology). At least three disciplines were involved in the successful completion of every project.

The New Dynamics of Ageing interdisciplinary programme is the first cross research council funded programme on ageing research in the UK and it is funded through this structure specifically because it brings together a broad range of disciplines under one unified programme.
The programme emerged out of the National Collaboration on Ageing Research which brought together scientists from across the disciplines to jointly address ageing research problems. Prior to its first call, the programme provided preliminary meetings to bring research teams together to write interdisciplinary proposals and importantly it provided an extended call period to enable these complex proposals to be developed.

In Germany, BMBF requires development of interdisciplinary projects for some of its programmes. The Medical Networks of Competence in particular requires scientists and physicians to work closely together in key areas of disease for example Parkinson, Dementia etc. The aim of these networks is to bridge the gap between basic and clinical research, different medical fields as well as health care.

The BIKURA funding pathway was launched by the Israel Science Foundation to support small groups that are characterised by a new non-conventional attitude with interdisciplinary of high risk features. These include personal or institutional grants. The successful pilot was conducted over 5 years and was implemented as an independent programme.

Benefits to using this approach include:

- Funders have to find ways to stimulate interdisciplinary research to enable the full gains from knowledge to be reaped and improvements in the quality of life of older people to be achieved
- Successful funding applications often results in research groups continuing to work together.

Challenges and limitations of this approach:

- Interdisciplinary collaboration requires time to build successful collaborations and shared understanding but the life-time is often limited to five years
- Disciplinary barriers still remain due to lack of career opportunities for interdisciplinary researchers
- Scientific reviews may be difficult.

**The network level within programmes:**

### 5.3.3 Different methods to stimulate interdisciplinary collaboration

Research programmes can adopt several methods to foster collaboration between projects or to encourage new interdisciplinary proposals:

- Hosting programme workshops that include discussions about methods, approaches and finding and time to develop/identify links and potential collaborations between projects.
ERA in the UK ran a workshop which operated a method similar to speed dating in order to promote interdisciplinary collaboration. Each person has up to 5 minutes to spend with each person and then they have to move on to the next person. Over two hours each person gets to meet about 20 people and they have to decide whether they want to follow up things together or not.

- Organising projects into thematic clusters and supporting meetings between these projects to enable joint learning and collaboration.

The Finnish Research Programme on Ageing was a multidisciplinary programme that facilitated joint learning through the thematic grouping of projects.

The training level within programmes:

5.3.4 Interdisciplinary training for the promotion of newly established / early career researchers

Some programmes and institutes run specialist interdisciplinary training programmes for newly established researchers. This helps to develop the next generation of interdisciplinary ageing researchers. It also helps to bridge the gap between basic research and practical application in gerontology.

Since 2003 the Institute for Biomedical Ageing Research (IBA, Austria) offers a MD/PHD programme called ‘The ageing of biological communication systems’ at the Medical University of Innsbruck. Newly established / early career researchers acquire a specialisation in biomedical ageing research. They receive theoretical information on recent progress in medical gerontology and acquire practical skills by learning modern laboratory techniques. Students studying medicine, biology and chemistry are taught together resulting in the generation of an interdisciplinary bio-gerontology critical mass.
SECTION 6

THE INVOLVEMENT OF RESEARCH USERS

6.1 WHAT IS USER INVOLVEMENT?

The involvement of user groups in research necessitates a broad definition but at its most basic it refers to the processes by which individuals or organisations play a role in the research programme or project outside of their traditional role as research subjects.

When developing user involvement three key questions must first be considered:

1. What is the primary purpose for involving users in the programme?
2. Which types of users are important to involve in the programme?
3. What levels of the programme planning and implementation should users be involved in?

6.1.1 Why consider involving users?

An important value gained from involving users is that of enabling programmes and their projects to develop research issues which are of importance to older people and their representatives. The key benefits to involving users is that it enables research programmes and their projects to be relevant to the ‘real world’ and to develop policy relevant research that contributes to extending the quality of life of older people. A further key advantage concerns important links with dissemination. By involving target groups of research findings from the onset in programme planning and design, the implementation of results and the dissemination of findings may reach a broader audience than can be achieved by the programme and its scientists alone.

However, the involvement of users gives rise to significant challenges. The approach generates additional research costs and requires considerable resources and time for establishing support systems and structures for user involvement.

The Older People’s Programme in the UK came the nearest to achieving this aim, by designing and implementing the programme in partnership with older people, who formed the majority of the programme committee members.

Clearly the above outlined good practice may not be appropriate for every programme but it provides an interesting example of how research programmes can be run in partnership with users.

6.1.2 Which user groups should be involved?

Ageing research programmes can involve a broad spectrum of user groups ranging from:

- Older people
- Representatives of older people such as non-governmental organisations (NGOs)
- Policy-makers
- Research funders
• Service providers  
• Industry/produce producer representatives  
• Other researchers  
• Patient groups  
• Professionals such as heath care workers, social workers etc.

6.1.3 In what ways and at what level should users be involved?

Just as the diversity of users can be wide ranging the form and level of involvement can also vary greatly:

For example, some programmes involve users at the dissemination or commissioning stages only, while others maintained input from users throughout the programme via the reviewing of project progress reports and the involvement of older people as researchers, evaluators and planners.

Key forms of user involvement include:

• Membership of steering or advisory committees  
• Consultation on programme planning via feedback on policy documents or consultation workshops  
• Membership on commissioning panels  
• Review of proposals  
• Review of project progress reports  
• Involvement in dissemination plans  
• Involvement in programme workshops  
• Eligibility to apply for project funding in partnership with scientists  
• Recruitment of older people as researchers  
• Older people’s advisory groups  
• Running research programmes in partnership with user groups.

In addition to these levels of user involvement a programme must also choose whether it is to retain user involvement at the programme level or whether it also seeks to encourage or require its projects to involve users. For example:

While most programmes may require projects to involve users others, particularly in the UK, endorse the involvement of users as a core condition for attaining funding.

Differences are significant and these may vary according to programme priorities as well as organisational and national differences. The questions of who to involve, to what extent and at what level, programme or project, will need to be addressed when planning user involvement.

It should be remembered that user involvement can represent an additional but worthwhile drain on research programme time, resources and commitment.
Further if research programmes wish to continue to involve users, important issues of payment for research users time and skills and how to provide adequate funding for involvement processes need to be addressed.

Some of the standard and good practices below may be useful when planning future user involvement strategy.

6.2 STANDARD AND GENERALLY AGREED PRACTICES

It is expected that all ageing research programmes will involve users at some stage as appropriate to the objectives of the programme.

One useful and effective way of involving users concerns the developmental and planning stages of a programme.

Many research programmes find it useful to involve policy makers and funders at this stage. The UK Ageing Research Programme also involved older people and their representatives at this stage.

The Netherlands and Sweden provide interesting examples which may be considered as examples of good practice of how to involve users in programme development.

In Sweden the government appointed representatives of research user groups to the board of FAS where decisions about programme development are made. These representatives also reviewed proposals in review committees.

The above practice is considered useful since research users were able to give their views on the social relevance of projects. One pitfall associated with this practice relates to the issue that there was no separation of user groups involved in planning programmes and those involved in the assessment of projects. It may be useful to consider this issue when planning how to involve users.

In the Netherlands, ZonMw established an advisory board where representatives from older people’s associations and older people discussed the planning of programmes on ageing.

This approach builds in the views of users from the onset of research programme planning. The concerns of older people and their representatives may subsequently help to inform the development of research.

6.3 GOOD PRACTICES

There are some useful good practice examples from established programmes which are worthy of replication.
At Programme level

6.3.1 User involvement as a requirement for funding

User involvement is largely embraced by research funders in the UK, consequently they are leaders in the field of user involvement in Europe. All research programmes in the UK are required to build in elements of user involvement and policy relevance into their work plans.

Various UK ageing research programmes require projects to involve users, in some appropriate form, as a requirement for attaining funding. (See for example, GO, NDA, EQUAL, OPPUS and the Older Peoples Programme).

Benefits to using this approach include:

- Facilitates the effective development of person centered care and person centered services
- Ensures that research is more responsive in output
- Ensures that experiences of people are taken into account from the onset at the design stage of research otherwise there is a danger that researchers completely miss the point
- Continually reminds researchers/programme participants that research is about providing better quality of life for older people as end users
- Enables projects to produce findings that are beneficial (sometimes immediately) to end users who have been involved in the process.

Challenges and limitations of this approach include:

- Time and financial commitment is needed to resource involvement throughout the process to, for example, recruit, support, build trust, common languages etc
- Researchers may need to change the way they think about research, how they interact with users and the language they use. They may have competing interests and are sometimes required to adopt a new research model
- Research funders and researchers may have to accept that other stakeholders have a voice in decision making processes in regard to how research is developed
- Retention of users may be an issue
- User involvement should be encouraged only where it is useful and not become a tokenistic gesture simply because funders require it. From the outset, careful consideration must be given to whether user involvement is appropriate and beneficial.

6.3.2 User involvement from the onset of the programmes

Key gains can be made from involving users from the beginning of the programme. An example of good practice is to involve users, consider their advice seriously and to subsequently show them how their advice has influenced the project.

In Austria the ZENTAS and LBISHM institutes work with politicians and social administrators in planning the programmes of research. ZENTAS develops projects in a cooperative form, starting from the point of a real need, either perceived by politicians and administrators or by the researchers.
Regular meetings and contacts are an integrative part of the programme. LBISHM involves politicians and administrators through directing their projects to meet the needs of these users, for example in developing guidelines or other instruments that have a practical impact.

In Italy, the ageing-Progetto finalizzato invecchiamento programme (which focused on policy and practice) involved the users platform while setting up and implementing projects. The aim was to make policy and practice user friendly.

Benefits of this approach include:

- Users develop a sense of ownership of results and a desire to see the work applied more generally
- It increases a programme’s chances of developing research projects that are relevant and of interest to user groups
- Intense communication and collaboration between researchers and research users guarantees a high degree of reciprocal learning that goes beyond the traditional forms of disseminating research results.

Challenges and limitations of this approach include:

- This form of collaboration may only be appropriate for very targeted and applied research
- With the expansion of ageing research there are dangers that older people will become rather ambivalent about being involved with research, especially if clear benefits/outputs of their involvement cannot be shown
- When advising politicians, it is important to consider the consequences and effects of the advice given on the basis of empirical knowledge.

6.3.3 Involving user groups in the reviewing of proposals

A further good practice is to bring service users together as a group to assess some parts of project proposals. See for example the OPUS programme in the UK and the FAS programme in Sweden which move away from traditional assessment models by obtaining collective views of groups on issues and subsequently develop joint recommendations.

6.3.4 Involving users in the implementation of results

In the Netherlands, user involvement is encouraged as a method for ensuring the effective implementation of programme and project results. This approach is also shared by many UK programmes.

Older people or their representatives sit on the board or programme committees. ZonMw set up a cross programme advisory board on ageing research, older people were also used as referees.
A further good practice approach to involving users in results implementation and dissemination concerns the inclusion of users during seminars. Programmes in France, UK, the Netherlands and Finland have endorsed this method.

The French programme on Technological Development and Ageing involved researchers, voluntary sector organisations and private business. The programme developed a user-friendly format and language for their seminars to enhance the involvement of user groups. Results were also presented in the popular press and magazines whose readership were predominantly older people.

The GO programme in the UK undertook a similar process by producing a report specifically targeted at older people and their representatives and produced user friendly short reports of project findings.

Benefits of this approach include:

- Programme and its projects gain from the experience of users and develop socially relevant research, effective implementation plans and results that are useful to user groups and to older people
- Programme results reach broad public audiences and help to raise public awareness of the value of research.

A challenge and limitation of this approach:

- Some groups of users are less familiar with research processes and it can be time consuming to develop user friendly seminars to involve them. However, seminars can be exclusionary in the absence of a user friendly format.

6.3.5 Taking user involvement to a new level

In the UK, the Older People’s Programme was uniquely designed with older people as the core group working in partnership with researchers in the development of projects. Arguably this programme has taken the involvement of older people to a new level.

From the outset, the Older People’s Programme involved older people in all stages of the project. A key example of good practice is the involvement of older people as commissioners of ageing research. Older people constituted the majority of participants in the Steering Group and they worked in partnership with the officers, external researchers and policy advisers to the programme.

The involvement of older people in this programme was extensive. In addition to their role in commissioning the research, they acted as researchers, reference group members (to inform policy and project development), members of advisory groups, peer reviewers (they commented and scrutinised findings and conclusions) and also as users of research findings.

Clearly this extent of user involvement is not feasible for all research programmes and indeed may not applicable to every area of ageing research.
Benefits of this approach include:

- Older people regarded their involvement as important both at a personal and a group level
- Older people set the programme agenda; they constituted the majority on committees which ensured that their views were given priority
- The steering group developed the standards for good involvement practice
- Older people developed confidence and new skills
- The programme showed that older people wanted to make decisions about their own lives and the services they require, and importantly they can play an important role in research that shape their lives.

Challenges and limitations of this approach include:

- The involvement of users during all stages of the process requires considerable time, resources and commitment
- Extensive user involvement takes time to develop
- Adequate funds are required
- Participants may confront a steep learning curve - specialist knowledge is required to involve users and users may need to develop specialist knowledge on research issues.

At Project level:

6.3.6 Keeping open the methods and level of user involvement

In many UK programmes, users have been involved in various stages of the research process within projects. However programmes have not been unified in terms of which types of users to involve and at what levels.

Some projects have employed an emancipatory research approach where they have involved older people as the researchers, as in the EQUAL, GO and Older People’s programmes.

For the most part, older people were seen as an integral part of the project.

For example the ‘Older Women’s Lives and Voices’ project (funded under the UK GO Programme) adopted an extensive form of user involvement and included the involvement of older women, from different ethnic backgrounds, as researchers. The women were involved fully in the research process from design, implementation, analysis and dissemination.

A minority of projects endorsed this intensive form of user involvement. The majority of projects drew upon more traditional forms of involving users for example via advisory groups and through dissemination. The relatively low level of involvement required consultation with older people, their representatives and service providers.
Benefits of this approach include:

- The development of usable research that retains strong links to policy and practice
- The employment of different user involvement approaches - programmes are required to involve a comprehensive range of relevant research users whereas projects may need to adopt a more targeted approach while considering which users to involve and to what extent.

A challenge and limitation:

- Funding user involvement sufficiently.
SECTION 7

INTERNATIONAL COLLABORATION

7.1 WHAT IS INTERNATIONAL COLLABORATION?

International collaboration is an activity involving agencies and institutions based in different countries who become collectively engaged in a common programme/projects with various objectives including maximising mutual benefit and promoting comparative research.

7.1.1 To what extent do ageing research programmes collaborate with each other?

One of the reasons for creating an ERA-NET in the field of ageing research is to address the absence of collaboration between Europe’s ageing research programmes. Not many examples of collaboration between ageing research programmes exist but there are a few interesting initiatives worthy of mentioning here.

7.1.2 Programme level examples

In some countries programmes are interacting, for example links between the Academy of Finland and the UK Research Councils (ESRC, EPSRC, BBSRC, MRC and AHRC) have been established. (In the field of basic science there is a jointly funded research programme between Germany and Israel.)

7.1.3 Project level examples

There are few examples of programmes which develop links between their projects and those of other ageing research programmes. Funding the travel of national researchers is the most supported form of international cooperation by programmes.

In the UK, the EQUAL programme developed an international dimension, for example the housing-related research links has strong links with other work in Europe and the Smart Homes project with work particularly in the US. Inclusive design research has enabled stronger links with Japan and more generally world-wide and the bio-engineering aspects of rehabilitation research has engendered valuable links with Canada. Similarly some GO programme projects had strong links with other countries.

The French programme ‘Ageing in the Work Place’ had extensive international collaboration and many of its projects collaborated internationally with Canadian, Portuguese and Belgian institutions. One of the projects participated in a study with the World Health Organisation.

A prevailing view of funding international collaboration is that it is potentially expensive unless it is specifically targeted. Consequently, many funding agencies/research councils do not support it.
Currently there is no international funding cooperation between ageing research programmes in Europe. The ERA-AGE project is the only form of collaboration that exists at present. On the other hand, international collaboration is well established on an institutional basis.

Institutions like FAS, the Academy of Finland, Institute for Biomedical Research and Vienna Institute of Demography in Austria have extensive international collaboration.

The Swedish Council for Working Life and Social Research (FAS) is a member of the European Science Foundation (ESF) and participates in a number of different areas, for example the European Social Survey which is a comparative study of social conditions and perceptions in several European countries and participates in the ESF Programme Quantitative methods in the Social Sciences. FAS takes a part in the Luxembourg Income Study which is a comparative database covering income distribution in different countries, launched in the early 1980’s.

Some large scale collaborations have also been developed by the Department of Health in the UK with the US Institute of Ageing on the English Longitudinal Survey of ageing (ELSA).

The Institute of Biomedical Ageing Research and the Vienna Institute of Demography in Austria are involved in many networks, for example, Immunology and Ageing in Europe and European collaborative projects.

7.2 GOOD PRACTICES

Due to the apparent absence of international collaboration between ageing research programmes, good practices are very difficult to identify. However, the following examples are worth considering when developing international collaboration between programmes.

7.2.1 Funding of overseas researchers

Under some programmes, researchers are eligible to apply for support for overseas study.

The Academy of Finland and the Swedish Council for Working Life and Social Research (FAS) have implemented measures that are aimed at promoting international collaboration and implement a grant system to support overseas scholarship as well as visiting grants for researchers from abroad.

Benefits of this approach include:

- Adding an international dimension to the research
- Facilitating contacts between researchers in different countries
- Adding European value.
Challenges and limitations of the approach include:

- International collaboration is expensive unless specifically targeted
- Programmes need specific funds allocated to international collaboration and networks
- Cultural and organisational differences can make collaboration difficult
- Different practices, such as review of applications, timing of calls, pose significant barriers.

7.2.2 International collaboration between projects

Some programmes foster international collaboration on a specific project level. Arguably, it is easier to collaborate on a specific thematic area on a project level and with a small group of researchers. However, no specific budget is allocated to this kind of international collaboration.
8.1 ABOUT RESEARCH ETHICS

Good quality research is undertaken in accordance with a set of recognised ethical principles which aim to protect the dignity, rights, safety and well being of research participants at all times. Participants may be involved:

- directly in research activities through physical invasive (e.g. surgery) and/or non-invasive research such as interviews, questionnaires, observational research) taking an active or passive role
- indirectly in research activities through the provision of personal data and / or tissue
- on behalf of others (e.g. parents, guardians, carers, supervisors in controlled environments such as prisons).

From the outset, the development of research programmes must be guided by relevant ethical procedures and protocols and the final document reviewed, approved (by a ethics review system/ procedure) and adhered to throughout the duration of the programme. Research programmes ought to have appropriate strategies in place to encourage partners and associated researchers to take responsibility for their own ethical practice.

8.1.2 What ethical guidelines and / or review system should programme managers use?

Ethical guidelines and procedures are endorsed by various institutions through which ethical advice and/or review may be requested:

(i) Research programmes that involve human participants in social research outside of health related disciplines may first approach academic institutions for ethical advice, review and approval such as:

- University-based Research Ethics Office and / or Committee
- National social research organisations such as the British Sociological Association (http://www.britsoc.co.uk/)
- Funders of social research such as the Economic and Social Research Council in Britain (http://www.esrcsocietytoday.ac.uk/ESRCInfoCentre/index.aspx)

(ii) For medical research involving human subjects, leaders of research programmes may seek advice and / or approval from for example:

- Declaration of Helsinki (developed by the World Medical Association) which provides ethical principles and guidance to physicians and other participants involving human subjects (www.wma.net/e/policy/b3.htm)
- National health and social care ethical regulations such as the NHS Central Office for Research Ethics Committees (COREC) in Britain (www.corec.org.uk/applicants/index.htm)
- Funders of research such as the Medical Research Council in Britain (http://www.mrc.ac.uk/index/current-research/funding-governance.htm)

8.2 STANDARD AND GENERALLY AGREED PRACTICES

Though ethical principles are endorsed differently from one institution to another, a set of standard generally recognized and agreed ethical principles can be identified when involving human subjects:

- Where a conflict of interest exists, the interests of the subjects of research prevail over those of science and society. This principle of involving participants is enshrined in the Council of Europe’s ‘Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (http://www.conventions.coe.int/Treaty/en/Treaties/Html/168.htm)
- Research must be generalisable having the potential to generate scientific understanding that may be the basis of improvements for human health and well being
- Research can only proceed if voluntary informed consent has been obtained from participants who are invited to participate in the research activity in question.
- Appropriate ethical approval must be sought by an independent review body for the research proposal.

8.3 GOOD PRACTICES

There are some important good practices currently in operation that are worthy of consideration.

8.3.1 Ethical review panels

Research funders may play active roles in ensuring high quality peer review standards:

    The highest standards of peer review are endorsed by the UK’s Medical Research Council (MRC) to ensure excellence of the research it supports and generalisability of research findings. The MRC provides regularly updated information about regulation and ethics to ensure that high standards in the conduct of research are maintained

In compliance with the standards endorsed by some research programmes, ethics review panels are used on a local and/or national and/or international level.
In Luxembourg, proposals under the Biotechnology and Health programme are systematically submitted to the National Ethics Committee for Research.

All projects receiving funding from Germany’s BMBF must have statements from ethics committees if the projects involve humans directly. These statements are often made by university ethics committees.

All projects funded by the Academy of Finland must have necessary ethical approvals. Researchers must describe ethical issues associated with their projects in their research plans when applying for funding. Ethical approvals are given by local ethical committees at universities, research institutes and hospitals.

Depending on the focus of the research, all UK-based proposals must meet ethical standards laid down by university and / or COREC guidelines. In addition, all health research involving NHS patients, human samples, patient data or NHS staff or facilities must meet the specific requirements set out in the Department of Health’s Research Governance Framework for Health and Social Care. All social care research also has to abide by the terms of the framework.

Italian based proposals must meet the ethical standards of local ethics committees.

8.3.2 Reviewing and removing bureaucratic procedures

The ethical review process can be confusing due to the inappropriate application criterion:

Some researchers find that ethics criteria do not apply to their area of research e.g. Israel human bioethical forms mostly focus on the drug admission procedure.

The MRC engages with Government and other regulatory bodies on existing or proposed regulation to ensure that important medical research is not hindered by excessive legislation.

8.3.3 Public involvement

Lay reader’s panels or surveys are sometimes set up in order to obtain end user’s comments on the ethics of proposed research

The UK’s Medical Research Council engages in dialogue with the public about the research it undertakes and possible methods through the use of opinion surveys in order to understand the public’s concerns.
Clarification of Concepts

Below is an explanation of concepts used in the Good Practice Guide

<table>
<thead>
<tr>
<th>CONCEPT</th>
<th>MEANING</th>
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<tr>
<td>Administrative barrier</td>
<td>An administration organisational procedure that may obstruct or prevent the action or will slow down the process.</td>
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<tr>
<td>Common pot</td>
<td>Funds from different organisations that are put together into a joint pot to be distributed on the basis of joint decision making.</td>
</tr>
<tr>
<td>Dissemination</td>
<td>The process of communicating information to specific audiences for the purpose of transferring knowledge and, in some cases, with a view to modifying policies and practices.</td>
</tr>
<tr>
<td>External expert</td>
<td>Person not employed by the organisation / agency or members of the board in question who, in some cases, may be invited to review or evaluate the quality of work / outputs.</td>
</tr>
<tr>
<td>IPR</td>
<td>Intellectual property rights - gives the owners of ideas, inventions and creative expression the right to exclude others from access to or use of their property.</td>
</tr>
<tr>
<td>Research ethics</td>
<td>The application of fundamental ethical principles to a variety of topics involving scientific research. Research ethical principles are usually embodied in research institutions’ guidelines and contain the information of awareness concerning ethical issues in research e.g. in social sciences. Research ethics form the focus of ethics committees who meet to assess the scientific quality of conduct of research proposals</td>
</tr>
</tbody>
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APPENDIX 2

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