



## TOOL 10

# Key recommendations for both ERNs and industry from the experiences of the first ERN-Industry pilots

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The recommendations below stem from the lessons learned in the process of initiating the first three Together4RD pilot projects (for the full report, see Tool 9 '[Experiences and Learnings from the first ERN-Industry pilots supported by Together4RD](#)'). They essentially function as an executive summary of that detailed report.

### Initiating a collaboration

Approach prospective partners as soon as possible – especially if the project is in response to a call or specific opportunity. This will allow input from all future partners in that very early project idea.

Embrace a co-creative process from the start, when it comes to reviewing and refining proposals and agreeing a research question. If possible, introduce a face-to-face meeting very early in the process, in which all are encouraged to review all the options on the table, in terms of how to orientate an activity, and share their perspectives, needs, and concerns.

Take time to do your research and understand as much as possible about your prospective collaborators:

- for industry parties, if you do not have deep knowledge of the ERN most connected to the condition(s) you are interested in, consider reviewing Tool 3, [What are ERNs?](#).
- For ERNs, take a look at Tool 5: '[What does Industry need in a collaboration with ERNs?](#)'.

For Industry - consider how best to pitch an ERN-focused project with colleagues internally (who may not have a strong understanding or awareness of ERNs) and ensure a smooth and early transition from policy to medical departments.

ERNs – be realistic and honest from the beginning in terms of how high a priority a particular condition is for your network. Ideally, share and publicise your research priorities as widely as possible. Be open to research out of the usual 'comfort zone', to address unmet needs in the field, but try to balance this with your realistic capacity and levels of internal ERN interest and expertise.

### Developing a robust and specific project plan

Be clear with a shared vision and mission statement at the start to align partners.

Be prepared to compromise and 'meet in the middle' when agreeing a concrete research question and firming-up a project plan.

Opening discussion around outcomes and impact early on should help to build transparent working relationships based on trust.

Understand that public and private actors tend to place value on different sorts of outputs.

- Industry - be prepared that ERN parties will likely place significant emphasis on generating peer-reviewed publications. ERN experts, often anchored in academic institutions as well as hospitals, have professional requirements to publish their work, This is an important marker of esteem, and thus publications will likely be a key output for any project.
- ERNs – consider how research can result in wider impact in terms of changing patient pathways and diagnostics practice, and outcomes beyond publications.
- ERNs – it is useful to accept that companies in the rare disease space tend to have goals and vision to improve the wider rare disease ecosystem, beyond simply developing and selling a product.

Do not underestimate the organisational and cultural differences and plan to take the time to understand what each other *desires and needs* from this collaboration.

Take time to discuss the expertise and skills each partner can bring to the collaboration – this is important, in order to build a fruitful collaboration in which all sides appreciate what the others can *bring* and to assess the skills across the full consortium (also allowing the identification of any gaps).

Think carefully about a realistic scope of work, depending on the timelines for completion: it may be helpful to view initial interactions between a given ERN and Industry as a proof-of-concept, starting relatively small but still meaningful, as an entry point for more elaborate projects down the line, e.g. once institutions have experience of forging these collaborations.

- Define small quick wins, achievable in a reasonable timeframe.

If it is the first foray into working with Industry for an ERN, accept that there may be setbacks and things may not develop as efficiently as one would wish – focus on the achievement of delving into a new area of activity, and plan for smoother progress on the next collaboration.

ERNs – accept that the Industry partner(s) will wish to have input to the scientific

development of the project plan, and should be viewed as an equal partner. Indeed, this should be welcomed, as it will bring significant advantages to the research, as it will give you access to the vast in-house scientific expertise but also expertise in medicines development, HTA, data science, and much more.

ERNs – be prepared to be vocal in co-developing a concrete project plan. Share your expert perspectives at every stage, as the industry partner will be seeking an active partnership with robust input.

Be prepared, in initial discussions especially, to ask challenging questions of the partners in your project – each party should understand the motivations and drivers of the other, and this means all should be willing to state what they would most like to achieve. This is important to build trust.

### Managing Resource Discussions

Do not postpone resource discussions, as uncertainty can cause delays and misalignment in project planning.

ERNs – it is important to have realistic expectation of both the level of resources industry can contribute to projects, and the way in which it does this. Avoid thinking of companies as purely funders of research. Companies are generally unable to dedicate large sums of money, for the subsequent definition of a detailed project plan – in fact it is the reverse: funding can only be found, internally, based on the contents of a proposed plan. Companies do not award funds as unrestricted grants, without any direct involvement.

Developing a concrete project plan as early as possible supports more efficient negotiations around budget and resources widely.

Identify project owners from both industry and ERNs who are sufficiently senior and have budget decision making power.

### Keeping the project-planning phase on track

Agree who will be the key drivers for each stage of the proposal initiation phase and project plan development.

It is highly recommended that dedicated project management time be allocated, to keep all partners on track. Standard progress tracking tools should be used, to agree timelines for each activity, and the project manager should be willing and able to follow-up when deadlines lapse, to keep the project moving forwards. It may be useful to involve external stakeholders (a third party) to support with this.

Regular virtual meeting should be established, to develop the more specific plan and drive the project forwards. However, these should be supplemented by at least one in-person meeting, across a day or two, ideally, to accelerate progress and address any uncertainties and make decisions.

Where projects involve more than one ERN centre, consider how those teams will work together most efficiently, making best use of everyone's expertise but also helping to keep a project on track. Consider focusing most of the administrative and bureaucratic and legal activity through one centre, for instance, but agree when and how individual experts and HCPs might take the lead to advance elements of the project.

Appreciate that delays can occur, on both side, and that these can cause major inconveniences (indeed jeopardize the project entirely) – both ERN and industry parties should therefore seek to avoid timelines becoming too long, by closely monitoring their progress and considering whether those working on a project are prioritizing it appropriately. In unavoidable periods of delay, it is imperative to maintain robust communication and inform each other of the situation, to manage expectations.

Companies should attempt to maintain key contacts working on any engagements with ERNs – although some staff turnover is normal, it is important for the rest of the consortium to have sight of who they are working with within each company.

Involve legal departments, from both/all sides, as early as possible.

Ensure that when entering into legal discussions, key project personnel are present at initial meetings of respective legal departments, to avoid misunderstandings.



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