



BRAIN TUMOUR IRELAND

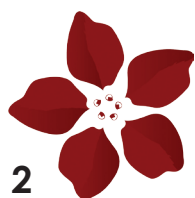
Strategic Plan 2016-2018

This plan has been developed with support from an independent charity:



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Foreword

Brain Tumour Ireland is seeking to grow and develop. We fully expect that by implementing this 3-year strategic plan (2016-2018,) we will achieve this objective.

We take pride in our accomplishments to date; yet we believe that we have even greater potential to realise. Through our strategic goals, our core challenge is to continue to serve the brain tumour community, whilst simultaneously growing and developing as an organisation. This document sets out precisely how we plan to do this, what we want to focus on, and the progress we expect to make.

In order to maintain service provision to our stakeholders in a manner that ensures high quality of service it is our intention to hire a national coordinator.

It is clear, as we enter our fourth year in existence, that there is an ever increasing need for organisations and professionals to work together for the benefit of those affected by brain tumours, including patients, their families and carers. With this in mind, we intend to build on our current excellent working relationships with other organisations throughout the life of this strategic plan, and beyond.

This strategic plan is a distillation of many hours of consultation, analysis and research, designed to ensure we are doing the very best we can for those we serve.

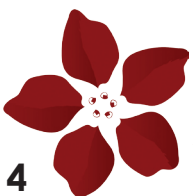


Natasha Smith
Chairperson

Acknowledgements

This plan has been developed with the engagement of Brain Tumour Ireland's stakeholders, friends and colleagues. Brain Tumour Ireland would like to thank everyone who took the time to input into this strategy.

Brain Tumour Ireland is currently an all-voluntary organisation and we would like to acknowledge the time, dedication and commitment of all of our volunteers on the Board, those who fundraise for us and those who participate in fundraising events. We look forward to working with you all in bringing this challenging plan to fruition over the coming years.



Brain Tumour Ireland: Vision, Mission and Values

About Us

The charity was founded in 2012 by a small group of people caring for a family member, Ronnie Fehily, who was sadly lost to a brain tumour in early 2012. As a national voluntary organisation our aim is to continue to fight the battle against the disease in her honour. Through Brain Tumour Ireland (The Ronnie Fehily Foundation), we hope to create a place where people can come for up-to-date information, guidance and support.

Vision

Brain Tumour Ireland envisions a society where all people affected by brain tumours are treated with dignity and respect, and have access to effective treatment, quality services and up-to-date information.

Mission

Brain Tumour Ireland's mission is to provide information and support to people with brain tumours, their carers/family/friends, as well as to medical and other relevant professionals. We aim to raise awareness of brain tumours, and advocate for Ireland to be a world leader in brain tumour research, diagnosis, treatment and care.

Values

Inclusive and non-discriminatory

We are inclusive. This means that we aim to communicate with the general public and the brain tumour community in a way that will be understood by people with language barriers, literacy difficulties or impaired cognitive functions.

We are non-discriminatory, meaning that in the provision of services, support and information, we do not discriminate based on gender, religion, sexuality, ethnicity, ability, family status, marital status or membership of the travelling community.

Open and transparent

Brain Tumour Ireland is open in its governance and financial activities; we publish our annual accounts showing how our stakeholders' contributions are spent for the benefit of the brain tumour community. Our policies and procedures are formulated in such a way as to ensure good governance and at all times we seek to be compliant with the Governance Code for non-profit organisations.



Ambitious and forward thinking

Brain Tumour Ireland is committed to supporting progress in relation to brain tumour research and treatment. This means that we actively seek opportunities to support brain tumour research and promote it through fundraising and raising awareness. We would like Ireland to be a world leader in brain tumour research and treatment.

Client focused

We prioritise people affected by brain tumours. Their needs inform all of our work, both internally and with clients and partners. We aim to provide high quality support and information to all those affected by brain tumours.

Peer-led

We believe that people affected by brain tumours are experts by virtue of their experience and are well-placed to lead Brain Tumour Ireland in achieving our objectives. This means that people affected by brain tumours, including patients and their families/ carers, are represented at Board level in the organisation, and regularly consulted in decision making and planning for the organisation.

Partnership-focused

We value partnership with other organisations in Ireland and abroad, whose aims are similar to those of Brain Tumour Ireland. Wherever possible, we seek out opportunities to share knowledge, increase efficiency and improve our services by working with other organisations.

What We Do

In order to achieve our mission, we currently undertake a number of activities, upon which we plan to build over the coming years. Currently, these include:

Fundraising events

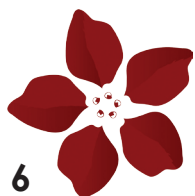
Our fundraising committee organises fundraising events annually. We also facilitate supporters of Brain Tumour Ireland around the country to host their own fundraisers and we do our utmost to support them.

Information provision

We have a website and email address which provides information and support for people affected by brain tumours, including patients/families and professionals. Our email service successfully signposts those who contact us to a range of relevant services throughout the country.

Wellness events

We have run a number of wellness events around the country. These events are for people living with brain tumours and those who care for them. At these events, people are given access to holistic therapies, information and support as well as an opportunity to meet with others in similar circumstances. People



who have attended these events have reported experiencing a sense of solidarity with other participants and thereby reducing their feelings of isolation and stress.

Supporting research

Part of our fundraising goes towards supporting research into brain tumours. We are establishing links with a number of institutions involved in research.



Development of the Strategic Plan

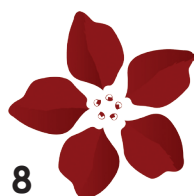
Development Process

Brain Tumour Ireland invited Quality Matters to support us in developing this strategic plan. Quality Matters is an independent charity, whose mission is to support other charities and social services to improve their organisations. The process included:

- A survey involving over 90 people affected by brain tumours (people living with brain tumours and people caring for others living with brain tumours)
- A survey involving almost 40 professionals working with people living with brain tumours or their carers.
- A number of facilitated planning and review meetings with the Board of Brain Tumour Ireland to review the organisations vision, mission and values, and the development of strategic actions for the coming three years.

Review of This Plan

A formal review of this strategic plan will be undertaken in summer 2017 to measure progress towards our stated goals.



Overview of Strategic Goals: 2016 to 2018

Overview

Our first strategic plan reflects our ambition for the development of this organisation under our three pillars:

- Provision of support and information on brain tumours and related issues
- Fundraising for needed services and brain tumour research
- Raising awareness of brain tumours among the public and professionals

In each of these areas, there are key strategic goals that support our vision for the organisation. As well as these three key areas, we have identified ambitious goals that will support our internal development in terms of governance and management of the organisation.

Strategic Goal 1: Develop the Support and Information Service

Develop a comprehensive, accessible and up-to-date online information service for people affected by brain tumours

Further develop the website to serve as an accessible information and sign-posting service for people diagnosed with a brain tumour, their carers, family and friends.

Strategic Goal 2: Provide a Range of Care and Support Services

Develop a new brain tumour support service in partnership with relevant stakeholders

In partnership with our stakeholders, develop a new brain tumour support service that is accessible to people living on Dublin's Northside and is developed based on best practice. This service will promote a sustainable model of peer-co-facilitation and be developed in a way that supports replication.

Develop and promote a calendar of care and information events in a variety of locations nationally

In partnership with local support groups or other professionals, we will where possible, develop and effectively promote a calendar of annual care events that meets the needs of our stakeholders.



Develop a small grants programme for people diagnosed with brain tumours

Develop a programme for providing small, once-off grants for individuals diagnosed with a brain tumour and in need of financial support. The small grants programme will contribute to costs related to treatment and care such as travel to and from appointments, accommodation, or access to psycho-social supports. This service will be managed in a way which is transparent, fair and timely. This action is dependent on fundraising success.

Review the need for an online support group

Undertake a needs analysis for an online support group and if a need exists we will pilot an online support group. This action should be taken in partnership with groups/ organisations that have experience in successfully running similar online support groups operating under good practice.

Strategic Goal 3: Effectively Engage Volunteers

Develop a volunteer strategy and policy

Develop a volunteer strategy, which engages and supports volunteers and those who fundraise on behalf of Brain Tumour Ireland.

Strategic Goal 4: Raise Awareness of Brain Tumours Among the Public, Professionals and Policy Makers

Develop an annual brain tumour awareness day

Develop a brain tumour awareness day, engaging all relevant partners and stakeholders to build this into an annual event of national significance.

Develop a calendar of brain tumour awareness initiatives throughout the year

Develop and promote a calendar of initiatives throughout the year that will facilitate opportunities to increase awareness of brain tumours and increase fundraising opportunities for the organisation.



Strategic Goal 5:

Develop Brain Tumour Ireland Governance, Management and Structures

Achieve the Governance Code

The Board will work towards achievement of the Governance Code for Community and Voluntary Organisations to ensure we achieve the highest standard of governance and oversight. This includes the development of clear financial policies, procedures and mechanisms for increasing our transparency to our fundraisers and beneficiaries, as well as further developing the mechanisms for running an effective Board.

Hire a National Coordinator

Develop a plan to employ a National Coordinator with key responsibilities in the areas of fundraising, development of service provision and coordination of volunteers.

Develop a fundraising strategy and fundraising pack

Develop a fundraising policy and strategy outlining how the organisation will become sustainable through its own fundraising activities including seeking philanthropic funding opportunities and sponsorship. The strategy will also include a fundraising pack for volunteers, to support them as they engage in fundraising opportunities on behalf of the organisation.

Create a Brain Tumour Ireland membership list

Create a membership database that supports effective communication with stakeholders and beneficiaries of Brain Tumour Ireland and supports the organisation to evidence its reach and impact.

Strategic Goal 6:

Support Research

Fundraise for research which supports better understanding of brain tumours and treatment

We will work to support research into brain tumours, their causes and treatment. In the lifetime of this strategic plan we will continue to fund the following project in conjunction with the Royal College of Surgeons in Ireland: '*Generation of glioblastoma (GBM) patient sample biobank and establishment of patient-derived cells for the testing of novel therapies*'. This project aims to develop a biobank of samples supporting long term research into brain tumours.



Detailed Plan and Timeline for Strategic Goals

Strategic Goal 1: Support and Information Service

Develop a comprehensive, accessible and up to date online information service for people affected by brain tumours

Further develop the website to serve as an accessible information and a sign-posting service for people diagnosed with a brain tumour, their carers, family and friends.

Step	Lead	Time to start action	Outcome / KPI
Map service provision in relevant services through research and develop a comprehensive, accessible sign-posting service online.	Board	2016: Q2	Detailed online service map Successful partnerships formed
Find an appropriate contractor or volunteer to develop high quality content for the website on: brain tumours, treatment, services and supports. Establish an expert review panel to approve new content.	Board	2016: Q2-4	Expert reviewed website section on medical and psycho-social information on brain tumours
Develop a communications policy that includes procedures for the update, monitoring and review of the website that will be then managed by the National Coordinator.	National Coordinator	2017: Q1	User and professionally reviewed website report



Strategic Goal 2: Provide a Range of Care and Support Services

Develop a new brain tumour support service in partnership with relevant stakeholders

In partnership with Beaumont Hospital, develop a new brain tumour support service that is accessible to people living on Dublin's Northside and is developed based on best practice. This service will promote a sustainable model of peer-co-facilitation and be developed in a way that supports replication.

Step	Lead	Time to start action	Outcome / KPI
Establish working agreement or memorandum of understanding in partnership with stakeholders for the development, delivery and review of a pilot peer-led brain tumour support service.	National Coordinator	Q2: 2016	Memorandum of understanding established
Develop a project guidebook for provision of an evidence based support service.	National Coordinator	Q3: 2016	Programme policies and procedures agreed
Once the guidebook is agreed by all parties, develop and provide the training and supports necessary for roll out of the support service.	National Coordinator	Q4: 2016	Any staff or volunteers engaged receive required training in the project in line with the project guidebook
Establish a pilot programme involving client engagement, service provision and data collection throughout the process to support the review.	National Coordinator	Q4: 2016	Support service established and open to service users
Review the pilot service after six months and again after one year. Develop a brief report with findings and publish on website.	National Coordinator	Q4: 2017	Project review with recommendations
If the review shows the programme to be successful then explore whether there is need for this support in other areas. If a need is identified, roll out the model to other areas.	National Coordinator	Q1: 2018	Project established



Develop and promote a calendar of care events in a variety of locations nationally

In partnership with local support groups or other professionals, we will where possible, develop and effectively promote a calendar of annual care events that meets the needs of our stakeholders.

Step	Lead	Time to start action	Outcome / KPI
<p>Develop a brief guidebook/policy in relation to running Brain Tumour Ireland care events which includes:</p> <ul style="list-style-type: none"> - Engagement of partners - Promotion of events - Types of services provided - Management of health and safety risks and incidents - Promotion - Volunteer engagement and management - Measuring success / outcomes 	National Coordinator	Q1: 2016	Clear guidebook outlining how to run Brain Tumour Ireland care events
<p>Develop an annual calendar of events that responds to members' needs, including adult and paediatric services. Identify key partners in all cases and develop promotion strategies for each area. Advertise the calendar of events on the website in January of each year.</p>	National Coordinator	Yearly	Annual calendar is agreed and promoted
<p>Deliver and evaluate events, using surveys. This will support improvement of services and planning.</p>	National Coordinator	Yearly	Ongoing quality improvement of service delivery



Develop a small grants programme for people diagnosed with brain tumours

Develop a programme for providing small, once-off grants for individuals diagnosed with a brain tumour and in need of financial support. The small grants programme will contribute to costs related to treatment and care such as travel to and from appointments, accommodation, or access to psycho-social supports. This service will be managed in a way which is transparent, fair and timely. This action is dependent on fundraising success.

Step	Lead	Time to start action	Outcome / KPI
Develop a guidebook/policy detailing how the small grants programme will be run, specifically on how: <ul style="list-style-type: none"> - It is advertised - Applications are assessed in a way which is fair, transparent and timely - The process is reviewed and improved - Outcome data is collected to show the value of the programme 	Board	Q2: 2017	Clarity and transparency on all elements of the process
Fundraise for the small grants programme as part of the organisations fundraising strategy.	Fundraising committee	Q2: 2017 ongoing	Increase in funding available for small grants programme
Launch the small grants programme ensuring optimum stakeholder awareness.	Board	Q1: 2018	People with brain tumours and their families are aware of Brain Tumour Ireland's small grants fund
Review the fund and the outcomes to ensure that the small grants programme has the best possible impact.	Board	After one year and then every two years.	Information is available to support ongoing improvement of the programme



Review the need for an online support group

Undertake a needs analysis for an online support group, and if a need exists pilot an online support group. This action should be taken in partnership with groups / organisations that have experience in successfully running similar online support groups.

Step	Lead	Time to start action	Outcome / KPI
Undertake a needs analysis of members to explore whether an online support group would be beneficial to them.	National Coordinator	Q4: 2017	Clarity and transparency on all elements of the process
If a need exists, establish a project plan engaging organisations or groups with expertise in supporting online groups. This is to include all resourcing and quality related details.	National Coordinator	Q1: 2018	A clear project plan for the pilot
Pilot the online support group for a year, with a review occurring after six months, and again after one year. A brief report is to be developed for the Board on the impact and sustainability of the group.	National Coordinator	Q2: 2018	Pilot of group, review and brief report



Strategic Goal 3: Effectively Engage Volunteers

Develop a volunteer strategy and policy

Develop a volunteer strategy which engages and supports volunteers and those who fundraise on behalf of Brain Tumour Ireland.

Step	Lead	Time to start action	Outcome / KPI
Run a volunteer seminar as part of the strategic plan launch in order to engage volunteers in future actions within the plan.	Board	Q1: 2016	Engagement of volunteers in the new plan
Develop a volunteer management guidebook which outlines: how volunteers' positions are advertised, how volunteers are recruited, how group supervision is provided, and all other relevant issues related to management of volunteers.	National Coordinator	Q3: 2016	Volunteer guidebook including clear policies and procedures
Include advertisement of volunteering roles on the website; once redeveloped.	National Coordinator	Q4: 2016	Volunteer fundraising section of the website
Volunteer feedback and review process is to be developed and implemented every 1 – 2 years to ensure Brain Tumour Ireland is engaging volunteers in a way that is mutually beneficial to all.	Board	Q4: 2017	Regular report on volunteer satisfaction and potential for improvements



Strategic Goal 4: Raise Awareness of Brain Tumours Among the Public, Professionals and Policy Makers

Develop an annual brain tumour awareness day

Develop a brain tumour awareness day, engaging all relevant partners and stakeholders to build this into an annual event of national significance.

Step	Lead	Time to start action	Outcome / KPI
Identify partners and establish a coalition or steering committee to develop a plan for the initial growth and piloting of National Brain Tumour Awareness Day.	Board	Q2: 2017	Steering Committee or coalition established
Plan a series of national events and media campaigns to pilot in year one.	Board with National Coordinator	Q3: 2017	Plan for the first National Brain Tumour Awareness Day established
Run the first National Brain Tumour Awareness Day.	Board	2018	Regular awareness day established

Develop a calendar of brain tumour awareness initiatives throughout the year

Develop and promote a calendar of initiatives throughout the year that will facilitate opportunities to increase awareness of brain tumours, and increase fundraising opportunities for the organisation.

Step	Lead	Time to start action	Outcome / KPI
Establish a calendar of initiatives and publish on the website in January of each year.	National Coordinator	Q4 each year	Clarity for all stakeholders on upcoming initiatives/ activities
Ensure the website is developed to support fundraisers and volunteers to register their initiatives on the site.	Board	Q4: 2016	The website supports the strategy
Notify membership mailing lists with quarterly reminder of activities nationally.	National Coordinator	ongoing	Clarity for all stakeholders on upcoming initiatives activities



Strategic Goal 5:

Develop Brain Tumour Ireland Governance, Management and Structures

Achieve the Governance Code

The Brain Tumour Ireland Board will work towards the adoption of the Governance Code for Community and Voluntary Organisations to ensure we achieve the highest standard of governance and oversight in this organisation. This includes the development of clear financial policies, procedures and mechanisms for increasing our transparency to our fundraisers and beneficiaries, as well as further developing mechanisms for running an effective Board.

Step	Lead	Time to start action	Outcome / KPI
Sign up as an organisation on the 'adoption journey' to becoming governance code compliant. Advertise on the website that the organisation is on the adoption journey as per recommendation by The Governance Code.	Board	Q2: 2016	Clear public record of the intention to attain the governance code
Recruit new Board members that fill the skills identified through the board skills audit in relation to legal, HR and fundraising experience.	Board	Q2 – 4: 2016	New board members join the board with the required skills
Develop a guidebook to outline all relevant processes and systems in relation to governance of Brain Tumour Ireland, to include although not be limited to: 1) Board membership issues such as rotation, skills audit 2) financial oversight and transparency.	Board	Q2: 2016	A guidebook outlining all elements of governance in simple and clear language
Cross-reference the guidebook and the new structures against the Memorandum and Articles of Association; adapt Memo and Arts as required, with legal support where necessary.	Board	Q3: 2016	Memorandum and Articles of Association are updated to reflect current structures and practices
Self-assess : review the service against the Governance Code, address any outstanding issues.	Board	Q2: 2018	Checklist of progress and identification of any outstanding issues
Once achieved include a declaration on the website stating that Brain Tumour Ireland has self-assessed as compliant against the Governance Code.	Board	Q2: 2018	Publically available information on compliance



Hire a National Coordinator

Develop a plan to employ a National Coordinator with key responsibilities in the areas of fundraising, development of service provision and coordination of volunteers.

Step	Lead	Time to start action	Outcome / KPI
Develop a series of employment related policies/handbook, including although not limited to: Recruitment and selection <ul style="list-style-type: none"> ● Leave ● Disciplinary and grievance ● Performance management and support ● Health and safety 	Board	Q2: 2016	Required employment policies in place
Recruit a National Coordinator in line with strategies and policies agreed.	Board	Q2: 2016	National Coordinator hired
Provide a clear work plan, expectations, support structure and review process to ensure successful probation period.	Board	Q3: 2016	National Coordinator inducted successfully



Develop a fundraising strategy and fundraising pack

Develop a fundraising policy and strategy that effectively outlines how the organisation will become sustainable through its own fundraising activities including seeking philanthropic funding opportunities and sponsorship, as well as supporting volunteers to engage in fundraising opportunities on behalf of the organisation through the provision of a fundraising pack.

Step	Lead	Time to start action	Outcome / KPI
Develop a fundraising policy that outlines the range of mechanisms used by the organisation to generate income including local event based fundraising, philanthropic funding and seeking statutory funding and how these are undertaken in line with good practice.	Board	Q2: 2016	A policy that outlines how the organisation meets good practice in fundraising
The Fundraising Committee, a subgroup of the Board, is to establish a fundraising strategy for the period of the strategic plan.	Fundraising Sub-Committee	Q2: 2016	An implementable fundraising strategy for Brain Tumour Ireland
Develop a fundraising pack to be made available to volunteers that outlines how volunteers can fundraise on behalf of the organisation considering: <ul style="list-style-type: none"> - Branding and image - Standards for fundraising - Transparency of financial activities required - Supports available from Brain Tumour Ireland - Communications with Brain Tumour Ireland 	Board	Q3: 2016	A succinct and informative pack that volunteers can use to raise funds for Brain Tumour Ireland
Undertake actions as stated in the fundraising strategy.	National Coordinator	Ongoing	Ongoing fundraising work to support the organisation to provide quality services to people with brain tumours and their family



Create a Brain Tumour Ireland membership list

Create a membership database that supports effective communication with stakeholders and beneficiaries of Brain Tumour Ireland and supports the organisation to evidence its reach and impact.

Step	Lead	Time to start action	Outcome / KPI
<p>In order to be able to evidence the beneficiaries of the service and its supporters, Brain Tumour Ireland will develop a list of members in line with data protection. Membership is free and members will receive information updates and free entry to the events and groups etc.</p>	<p>Membership and Administration Volunteer</p>	<p>Q2: 2016</p>	<p>A comprehensive list of people who receive supports from Brain Tumour Ireland to assist the service in showing its reach and impact</p>
<p>This list will be updated every two years.</p>	<p>Membership and Administration Volunteer</p>	<p>Annually</p>	<p>This list is kept relevant and up to date</p>



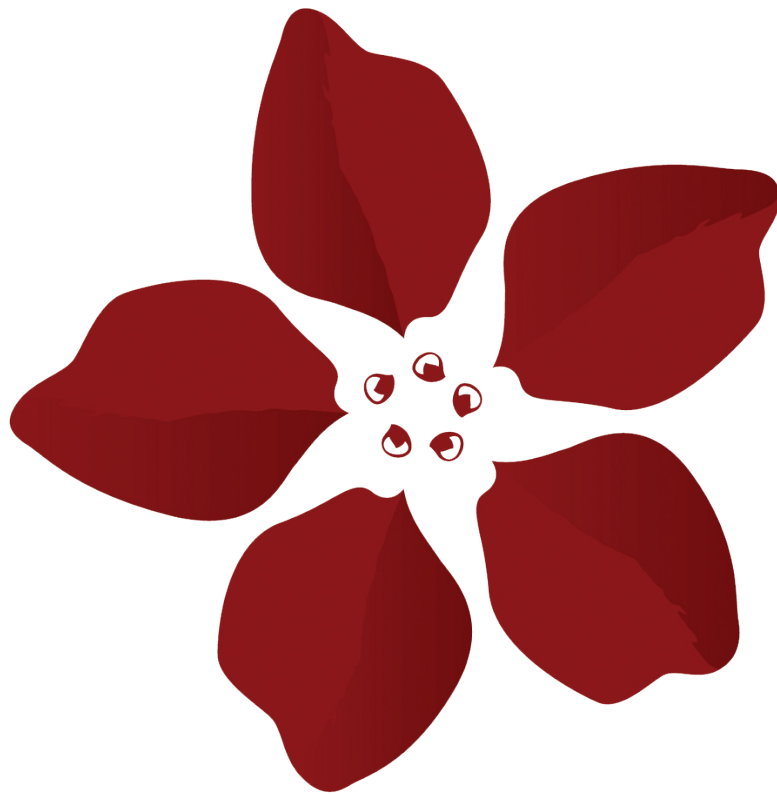
Strategic Goal 6: Support Research

Fundraise for research which supports better understanding of brain tumours and treatment

We will work to support research into brain tumours, their causes and treatment. In the lifetime of this strategic plan we will continue to fund the following project in conjunction with the Royal College of Surgeons in Ireland (RCSI): '*Generation of glioblastoma (GBM) patient sample biobank and establishment of patient-derived cells for the testing of novel therapies*'. This project aims to develop a biobank of samples supporting long term research into brain tumours.

Step	Lead	Time to start action	Outcome / KPI
Continue to fund the research project named above in conjunction with the RCSI. This action is dependent on successful fundraising.	Board	Q2: 2016	Completed research project resulting in published articles and an operational biobank





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