P3G MODEL FRAMEWORK FOR BIOBANK GOVERNANCE (2013)
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I. BACKGROUND

In order to further its mission to lead, catalyze and coordinate international efforts to optimize the use of biobanks, the Public Population Project in Genomics and Society (P³G) has updated the 2008 model framework for biobank governance.¹ The proposed governance framework incorporates an analysis of the last five years of legislation, policies and literature that have influenced and shaped the governance of biobanks, and reflects the P³G’s vision of global access to research tools. Moreover, the practices of current P³G members were reassessed, including their governance mechanisms and changes in policy since 2008 (www.p3g.org/resources/biobank-catalogues). It is our hope that this model framework will provide a useful tool for the next generation of population biobanks.

II. INTRODUCTION

There is voluminous literature on the need for a new model of governance for modern biobanks. Today, the extent of sample and data sharing required for biobank research is unprecedented,² raising ethical and regulatory challenges.³ Nevertheless, biobanks are beginning to provide access for research, even while their procedures and tools continue to generate ethical and legal uncertainty.⁴ Moreover, “established concepts of research ethics [are] ‘stretched to their limits’ by the flood of information created by recent advances”.⁵ Thus, existing norms, both ethical and legal, inadequately regulate biobanking.⁶

This criticism stems from the national regulation of biobanks, which creates heterogeneous systems across countries and a lack of standardized biospecimens and data, inhibiting

transnational sharing and collaboration. The result is legal fragmentation due to the multiplicity of normative sources and local practices. These variable and occasionally inconsistent norms have created a patchwork of regulation. For example, in Europe, a study of the various levels of biobank governance revealed that several models of policy are used, depending on the legal systems in which they operate. Similarly, in Sub-Saharan Africa, the regional variability of biobanking guidelines was considered to be an obstacle to collaboration and success of biobanking initiatives in Africa. Similarly, research ethics boards are culturally and regionally variable, which further hinders international collaboration and results in duplicative efforts.

While the regulation of biobanks is regionally variable, research is increasingly global in nature, requiring research governance mechanisms that are also global in nature. The present challenge for a biobank is to ensure compliance with all applicable norms. Thus, the main

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problem with existing governance mechanisms is their national and parochial nature. Other challenges include developing standards, oversight mechanisms, participant interest and articulating the main roles and responsibilities of the actors involved.

Governance plays a crucial role in addressing the social and ethical challenges of biobanking. It remains pivotal to maintaining public support and financing, and ensuring the security and protection of participants, respect for cultural perspectives and the availability of biospecimens and data for research. Moreover, proper governance is key to the success of a biobank. Nonetheless, few efforts have defined what constitutes a proper governance framework in practice. Without a proper governance framework, population biobanks may unduly add multiple layers of oversight, limiting their ability to conduct research and their overall utility. Various theoretical approaches to governance have been advanced, considering the changing nature of post-genomic medical research and the growing need for global research networks, notably e-governance, reflexive governance and anticipatory governance.

III. THEORETICAL APPROACHES TO GOVERNANCE

Numerous theoretical approaches help to conceptualize the challenges faced by biobanks when setting their governance structures.

E-governance, or digital governance, is based on a digital global governance system whereby existing mechanisms and committees continue to exist, but do not always come into play. This approach hinges on rethinking the conceptual basis of research governance and using information technology (IT) more efficiently as a mechanism for governance. Accordingly, we should move away from paper-based systems and think in terms of data flow and research portals that enable sharing and access. Secondly, we should move away from “the ‘one researcher, one project, one jurisdiction’ model” to the recognition of research networks. IT can be used to direct and allow research proposals based on “ELSI appropriate behaviors”.

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15 Kaye, supra note 12; Kaye, supra note 6 at 379.
16 European Commission, supra note 9.
18 Ibid at 317; Staunton & Moodley, supra note 11.
19 Gottweis & Lauss, supra note 9.
20 Hawkins & O’Doherty, supra note 17; O’Doherty et al, supra note 6.
21 Kaye, supra note 6 at 379; Parchomovsky & Mattioli, supra note 8; Gibbons, supra note 9 at 314 & 345; Gottweis & Lauss, supra note 4 at 187; O’Doherty et al, ibid 367; European Commission, supra note 9.
22 Kaye, supra note 6 at 381.
23 Ibid at 380.
24 Ibid.
25 Ibid at 381.
26 Ibid.
rather than having to incessantly rely on an oversight committee. Instead, there would be a triage of research proposals and expert review based on the principle of do no harm. This global system does not dismiss the principles and mechanisms that have evolved over time; rather, it combines them in an efficient way whereby certain mechanisms need not be triggered, resulting in a system of triage, digital governance and expert review consistent with current foundational ethical principles.

A second theoretical approach is reflexive governance, intended to adapt to the existing challenges generally faced by biobanks. Reflexive governance is premised on the principles of integrity of purpose, proportionality of action and reflexivity of approach, whereby mechanisms are developed to permit biobanks to operate despite uncertainty and to adapt with time to ensure “good governance”, defined as:

1. designing-in interoperability with respect to scientific and governance approaches,
2. designing-out approaches that are restrictive of sharing, cooperation, flexibility and mutuality,
3. establishing policies and procedures to promote actively the use of the resource in keeping with its original purpose,
4. ensuring the longevity of the biobank through carefully managed access policies and arrangements and stewardship of the resource, and
5. ensuring that governance policies and mechanisms remain fit for their purpose over time.

Reflexive governance “must operate in tandem with the development of scientific endeavor” while encouraging cooperation and compliance, and it is dependent on those governed and those governing being receptive, responsive and open. Legal regulation is therefore not necessary.

Similarly, anticipatory governance is another theoretical approach that acknowledges the uncertainty surrounding technological and scientific innovation. Anticipatory governance considers human values and stakeholders, constituting a form of shared/participatory

27 Ibid.
28 Graeme Laurie, “Reflexive governance in biobanking: on the value of policy led approaches and the need to recognise the limits of law” (2011) 130:3 Human Genetics 347 at 347.
29 Defined by Laurie as “[focusing] on the [trust] relationship between those with responsibility for the biobank and those who have contributed to it or might expect to benefit from it, which could include society at large”, ibid at 349.
30 Ibid.
31 Ibid at 352.
governance, “‘extended peer review’ and social embedding”\textsuperscript{33} of innovations, going beyond expert opinion. Other key features of anticipatory governance include:

- early upstream engagement;
- notion of “coproduction” of knowledge by society and science;
- anticipates future developments and issues with the goal of adapting; and
- consideration of expert opinion and public engagement.\textsuperscript{34}

These theoretical approaches help conceptualize the challenges faced by biobanks and set common standards, but they offer limited guidance in terms of concrete steps, mechanisms and measures that should be adopted by biobanks to attain these standards. Therefore, we adopt a practical approach to governance, setting out core elements to biobank governance. We build on the recommendations and the generic model for biobank governance advanced in 2008, incorporating public perception as a key element in governance, as well as these new approaches. This paper will outline the principles and procedures that inform the creation and implementation of governance mechanisms (core elements) used by biobanks. These mechanisms are either external or internal to the biobank and may vary throughout the lifecycle of the biobank.\textsuperscript{35}

IV. GOVERNANCE MECHANISMS AND THE LIFECYCLE OF A BIOBANK

The lifecycle of a biobank can be divided into three stages: 1) Conceptualization and design of the biobank (before); 2) Building the biobank (during); and 3) Using the biobank (after) (Figure 1).\textsuperscript{36} Since the needs of the biobank differ from inception to the operational phase, governance needs and mechanisms vary during each of these stages. While the elaboration of a governance framework is not a one-size-fits-all approach, certain governance mechanisms cut across stages of the biobank’s lifecycle, as with ethics approval for example, while other events are single occurrences, like the creation of committees.

1. Before: Conceptualizing and Designing the Biobank

The “before” period is the first stage in the lifecycle of a biobank and includes the planning, design and creation phase. A majority of the governance mechanisms used in this stage are external ones that the biobank must consider or respond to. For example, key regulatory concerns must be addressed, including enrolment, consent, proprietary interests and privacy.\textsuperscript{37} Moreover, an ordering process must be undertaken, including the creation of protocols, data

\begin{itemize}
\item \textsuperscript{33} Ibid.
\item \textsuperscript{34} Ibid at 414.
\item \textsuperscript{35} Gibbons, supra note 9 at 239; Wallce, Bédard & Knoppers, supra note 1.
\item \textsuperscript{36} Ibid.
\item \textsuperscript{37} Parchomovsky & Mattioli, supra note 8.
\end{itemize}
warehouses and databases. Very early in the process, there must be discussions with funders, an examination of applicable laws and regulations and public engagement. As plans are consolidated, formal applications must be made to funders and ethics committees for approval.

2. During: Building the Biobank

Once a design/plan has been created, the second step, the “during” phase, is building the biobank. The design is implemented, participants are recruited, samples are collected and banking begins. The governance focus shifts to the creation of internal mechanisms to manage the development and operations of the resource, such as the establishment of an executive committee, and scientific and ethics committees.

3. After: Using the Biobank

The third step is the “after” stage, where the samples and data are banked and it is time for researchers to access the bank and proceed to analysis. The biobank has become operational. At this stage, a data/sample access policy and intellectual property policies will have to be created and put in place. Methods for communicating the research results derived from biobank and for encouraging public input will also have to be considered.

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V. GOVERNANCE MECHANISMS & FRAMEWORKS

Throughout this lifecycle, governance frameworks regulate the processes and interactions between the various actors involved and include agreements, procedures, guidelines, laws, conventions, policies, social norms and institutions that define decision-making, accountability

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38 Gottweis & Lauss, supra note 9 at 64.
39 Wallace, Bédard & Knoppers, supra note 1.
40 Ibid.
Biobanking is at the intersection of multiple disciplines, actors, activities and issues, including medicine, science, as well as public and private interests. This intersection raises numerous questions that must be answered to determine the proper form of governance for a biobank, specifically, what should be the level of regulatory response? Who are the decision-makers? What is the extent of their role? How should responsibilities be shared between the various actors? What types of measures should be favored (incentives or restrictions)? The governance of biobanks is also about regulating the relationships between citizens, society, researchers and biobanks. These complex series of interactions are regulated by external and internal mechanisms (Figure 2).

The governance of biobanks is dynamic, meaning adequate governance must be tailored to the specific context of the biobank. Different biobanks will require varying forms and degrees of oversight and regulation. Nevertheless, the goal remains to create a system, capable of

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42 Rial-Sebag & Cambon-Thomsen, supra note 10 at 114 & 119.

43 Gottweis & Lauss, supra note 4.

44 European Commission, supra note 9; Wallace, Bédard & Knoppers, supra note 1 at 3.

45 Theo Papaioannou, “Democratic governance of genomics: the case of UK Biobank” (2012) 31:2 New Genetics Society 111 at 129-131; Hawkins & O’Doherty, supra note 17; Gibbons, supra note 9 at 339; Canadian Institutes of
adapting over time, for the efficient use of samples and data for the advancement of science, respecting the confines of law and ethics and the rights of persons.46

While this paper by no means intends to resolve the “lively debate”47 on the governance of biobanks, and while the literature is far from reaching a consensus on the matter,48 a generic model governance framework is proposed (Figure 3), taking into account the external and internal governance mechanisms illustrated above and explained below (Figure 2).49

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Biopreservation and Biobanking at 259; Rial-Sebbag & Cambon-Thomsen, supra note 10.

McHale, supra note 9 at 232.


1. External Governance Mechanisms

External governance mechanisms are those over which biobanks have no control. These mechanisms include binding and, in some cases, even non-binding sources of obligations and can generally be grouped into six categories (Figure 4).

![Figure 4. External governance mechanisms]

a) Public Perception

A biobank cannot operate without social acceptance. Public perception is now seen as a crucial consideration in the governance of a biobank. Transparency and accountability of the biobank ensure positive public perception, enhancing the legitimacy and trust in the biobank.

b) Socio-cultural Norms & Values

Socio-cultural norms and values also impact the existence and conduct of biobanks and are by definition culturally variable. Biobanks must conform to such norms and values, to ensure social acceptance and public participation. Examples include trust, respect for privacy, reciprocity and solidarity, as well as notions of ownership.

c) Legislation & Regulations

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50 Hawkins & O’Doherty, supra note 17; Rial-Sebbag & Cambon-Thomsen, supra note 10.
52 Rial-Sebbag & Cambon-Thomsen, supra note 10 at 127.
Within legal sources of governance, there are two approaches to biobanking: specific or general legislation. Certain countries\(^{53}\) have legislatively created and regulated biobanking, while others have relied on existing general legislation (e.g. data protection, privacy, research involving human subjects) or even professional self-regulation.\(^{54}\) Therefore, while not necessarily specific to biobanking, all countries have in place regulations, be it legislation, professional guidelines or other technical or ethics norms, that must be taken into account in the operation and oversight of a biobank. In short, external governance mechanisms include various legal, ethical and cultural norms, in addition to overarching international or intergovernmental ethical guidelines and codes of conduct.\(^{55}\) Moreover, numerous sets of standards, quality assurance mechanisms and best practices have been created to guide the operation of biobanks. Adhesion is generally voluntary.\(^{56}\)

d) **Funders’ Requirements**

Funders fall within many categories and their contribution can be public, private or charitable. Funders have their own guidelines and requirements that grantees and researchers must follow, as non-compliance may jeopardize the research project. Moreover, an indirect form of authority that governance funders possess is an ability to direct the path of science by allocating money to areas of interest to them (e.g. funding allocated to a particular disease or technology). Their most important influence in the context of biobanking is to require open access to such biorepositories.\(^{57}\)

e) **Scientific Peer Review**

The creation of a biobank must receive approval from a scientific peer review committee. This is often part of the funding process, where the review is organized by the funder and is crucial to this form of “infrastructure science”.\(^{58}\)

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\(^{53}\) Spain for example enacted the 2007 Law on Biomedical Research which regulates biobanking. See *Law 14/2007 of July 3, on Biomedical Research* at article 1(e) and Chapter 4.


\(^{56}\) See e.g. ISBER, *supra* note 46; NCI Best Practices, *supra* note 7; EuroBioBank, online: <http://www.eurobiobank.org>; OECD Guidelines, *ibid*.


f) Ethics and Privacy Review

Similarly, like all research, the creation of a biobank must receive ethics approval. Thus, an ethics committee (e.g. REB, IRB, REC, etc.) must approve the overall plan for the biobank, including its consent materials, recruitment plans, as well as privacy, communication and security measures. As plans change, additional review may be required.

2. Internal Governance Mechanisms

Internal mechanisms are created by the biobank itself to meet a requirement or fulfill its role, and regulate for example its mandate, operation and financing.\(^5^9\)

These mechanisms can largely be grouped into six core categories, found within most operational biobanks: a) Public Engagement Committee; b) Biobank Steering Committee; c) Scientific Advisory Committee, d) Ethics Oversight Committee; e) Laboratory Bio-safety Committee; and f) Data Access Committee (Figure 5).\(^6^0\)

There may also be other types of committees, e.g. looking at epidemiology, information and technology (IT) and data security.\(^6^1\) These oversight committees have specific roles and functions, with varied expertise.\(^6^2\) We propose a model framework for the governance of biobanks based on the six (6) core elements outlined above.

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\(^5^9\) Bédard et al, supra note 49.
\(^6^0\) Ibid at 220; See UK Biobank, online: <http://www.ukbiobank.ac.uk>; Generation Scotland, online: <http://www.generationscotland.org>; CARTaGENE, online: <http://www.cartagene.qc.ca>; BBMRI, online: <http://bbmri.eu>; Canadian Partnership for Tomorrow, online: <partnershipfortomorrow.ca>.
\(^6^1\) See Generation Scotland, UK Biobank, CARTaGENE and BBMRI for various organizational structures, ibid.
\(^6^2\) OECD, supra note 14; OECD Guidelines, supra note 55; NCI Best Practices, supra note 7.
a) **Public Engagement Committee**

Public engagement committees help researchers gauge the public’s acceptance or concerns with the biobank, enabling researchers to design their studies accordingly.\(^{63}\) This input fosters legitimacy and sustainability to the resource.\(^{64}\) While public engagement encapsulates public perception, the latter may not necessarily be actively sought out by the biobank and may remain an external governance mechanism.

Even prior to recruitment, public engagement can take various forms depending on the context and culture of the targeted country or population, including forums, citizen conferences, town hall meetings, surveys and committees. There is a need for both the launching and ongoing public support and engagement for the proper governance of population biobanks.\(^{65}\) Thereby more inclusive approaches to governance are required.\(^{66}\)

b) **Biobank Steering Committee**

The Biobank Steering Committee manages the day-to-day scientific and management operations of the biobank, including informing the public about its goals and activities, seeking the input of society and participants, and modifying its plans accordingly.

c) **Scientific Advisory/Oversight Committee**

Scientific advisory/oversight committees give advice on the scientific aspect of the biobank.\(^{67}\) Members can include experts such as geneticists, epidemiologists, ethicists and biostatisticians, often from other countries.\(^{68}\) Indeed, it is equally important that an independent International Scientific Advisory Committee provide advice on the science and governance of the biobank.

d) **Ethics Advisory/Oversight Committee**

Ethics advisory/oversight committees provide advice on the legal, ethical and social aspects of biobanking activities, overseeing the ethical conduct of the biobank (e.g. data protection

\(^{63}\) See for example Generation Scotland’s Public Consultation Program divided in various stages and aimed at exploring the public’s opinion on a range of issues tied to the use of genetics in healthcare, online: <http://www.generationscotland.org/index.php?option=com_content&view=article&id=61&Itemid=126>.

\(^{64}\) O’Doherty, Hawkins & Burgess, *supra* note 51.


\(^{67}\) Rial-Sebbage & Cambon-Thomsen, *ibid*.

\(^{68}\) See for example CARTaGENE’s International Scientific Advisory Board, online: <http://cartagene.qc.ca/en/governance>.
questions, consent issues, legal questions). Members may include lawyers, ethicists, social scientists and representatives of the population. The Ethics Oversight Committee is a “key oversight body common to most jurisdictions”, acting as a gate-keeper, deciding whether or not a research protocol can proceed.\textsuperscript{69} Depending on the legislation and data security mechanisms in place, the approval of the Ethics Committee may be required for access to data and samples. Moreover, the committee may be internal to the biobank, or be external and independent.\textsuperscript{70}

e) **Sample and Data Storage/Laboratory Practices Committee**

Sample and data storage committees oversee the quality control, quality assurance and data protection policies used when handling and storing samples, data from participants (e.g. questionnaires, body measurements, etc.) and derived data.\textsuperscript{71} A Laboratory Bio-Safety Committee should also be constituted to oversee the handling of samples (\textit{i.e.}, requirements for collection, storage, labeling, etc.).

f) **Data/Sample Access Committee**

Data/sample access committees oversee the processes allowing researchers to gain access to the biobank’s samples and data.\textsuperscript{72} Specifically, a Data/Sample Access Committee creates guidelines for access and reviews access requests made by researchers. It can be internal or external and independent from the biobank. Access policies vary, but are generally based on a notion of proportionality, balancing the needs of researchers with the potential benefits and risks to participants and society, reflecting the biobank’s concerns and priorities.\textsuperscript{73}

3. **Final Remarks**

While no one-size-fits-all, the following should be sought in order to create an adequate governance framework:

**Scientific Aspects**

- The research conducted will advance science and benefit society in the future.
- The biobank’s procedures and activities will receive independent scientific review.
- Researchers seeking access to the biobank will undergo scientific review of their

\textsuperscript{69} Kaye, supra note 6 at 379.

\textsuperscript{70} See for example the UK Biobank Ethics and Governance Council, online: <http://www.egcukbiobank.org.uk>;
Rial-Sebbag & Cambon-Thomsen, supra note 10; OECD Guidelines, supra note 52; Kaye, supra note 6; Fullerton et al, supra note 3.

\textsuperscript{71} See for example UK Biobank Sample Handling and Storage Sub-group discussed in Paul Elliott & Tim C Peakman, “The UK Biobank sample handling and storage protocol for the collection, processing and archiving of human blood and urine” (2008) 37:2 International Journal of Epidemiology 234.

\textsuperscript{72} OECD, supra note 14; OECD Guidelines, supra note 55.

\textsuperscript{73} Fortin et al, supra note 57 at 106.
research proposal at some level.

**Ethical Aspects**
- The confidentiality of personal information will be protected and consent will be obtained from participants.\(^74\)
- The biobank’s procedures and activities will receive regular and independent ethics review.
- All requests for access to the biobank will be reviewed at some level.
- The biobank will comply with all relevant legislation, guidelines and norms, further ensuring the protection of participants’ fundamental rights.

**Legal Aspects**
- The biobank will comply with all relevant legislation.
- The biobank will address the ownership or custodianship of the biological materials.\(^75\)
- The biobank will address researchers’ obligations and its own obligations.\(^76\)

**Expertise**
- There will be expert representation on all governance and oversight committees as required (i.e., epidemiologists, bioinformatics, sociologists, geneticists...).

**Communications & Reporting Aspects**
- Participants will be kept informed of the research conducted using their samples and data.
- Researchers gaining access to the biobank will have reporting obligations, notably having to report their general research results to the biobank for public dissemination.
- Participants will be able to register their comments, queries and complaints, with the assurance that any complaint will be addressed by the biobank.

The 2012 recommendations on biobank governance of the European Commission are also noteworthy and reflect many of the mechanisms, principles and theoretical approaches previously discussed:

- Develop a consistent, coherent legal framework that protects participants’ fundamental rights (privacy, data protection, use of human tissue);
- Better coordination and collaboration between national oversight bodies and mutual recognition of decision-making to eliminate unnecessary duplication of oversight and compliance requirements;
- Sustainable governance mechanisms to involve and engage the public to ensure continual participation, trust and support;
- Sustainable governance mechanisms for creating a relationship of reciprocity between biobanks and society;

\(^75\) Capron et al, *ibid.*
\(^76\) *Ibid.*
- New emerging governance bodies should be integrated into existing systems to develop a meta-governance for biobanking;
- Biobanks need to be embedded in the public healthcare structure as valuable resource for clinical care, personalized medicine and translational research;
- Greater investment in development of e-governance tools to facilitate sharing;
- Use of web 2.0 technologies to involve patients, participants and the public in the governance of biobanks to ensure trust; and
- New accreditation systems to reward/acknowledge efforts of scientists who build biobanks.\textsuperscript{77}

VI. CONCLUSION

The recent focus in the literature has been on creating networks to facilitate global research and international collaboration. It is therefore important to move beyond the uni-jurisdictional model of governance in existence. There is also a need for mutual recognition, requiring new strategies to regulate the relationships between citizens, societies and biobanks and avoid duplication of effort.\textsuperscript{78}

There exists no single ideal governance framework. Rather, governance must be tailored to the needs of the biobank and be capable of adapting over time. The identified six core elements can be found in most operational biobanks and can be adapted to the existing challenges of biobanking. Considering these elements, minimally, biobanks can follow general principles of good practice by creating a governance structure that responds to the needs and expectations of participants and the requirements imposed on them. Moreover, while there has been a call for harmonization of biobanking practices and policies, this feat is not currently possible considering cultural and legislative variations, and differences in organizational structures and funding.\textsuperscript{79} Thus, we must continue to consider all external mechanisms when creating and adopting internal mechanisms of governance, and keep in mind that the purpose of a governance structure is to facilitate, not hinder, scientific progress.

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\textsuperscript{77} European Commission, \textit{supra} note 9
\textsuperscript{78} Gottweis & Lauss, \textit{supra} note 4 at 187; European Commission, \textit{supra} note 9.
\textsuperscript{79} OECD, \textit{supra} note 14.
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Public Population Project in Genomics and Society (P3G), online: <http://p3g.org>.

**SECONDARY MATERIAL: OTHERS**


