

**Syntheses of large-scale biodiversity and health datasets to  
support evidence-based policy and address key societal challenges**

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## **ABOUT THE AUTHOR**

Muriel Rabone is a data analyst and researcher at the Natural History Museum (NHM) London, with particular focus on biodiversity in the Clarion Clipperton Zone and the neglected tropical diseases schistosomiasis and paragonimiasis. From 2011-2020 she worked on the Schistosomiasis Collection at NHM, a Wellcome Trust-funded initiative to build a global reference collection of schistosomes and intermediate hosts and facilitate research on this neglected disease. From 2021 to the present she has worked in the deep sea systematics and ecology group on externally funded projects and contributed to deep-sea invertebrate systematics papers. Before joining the NHM, her diverse career included roles in New Zealand at the Auckland Museum in marine collections, at the bioinformatics software company Geneious where she helped develop population genetics analysis tools, and freshwater and marine environmental monitoring for ecological and geological consultancies. Since 2020, she has co-led the Deep Ocean Stewardship Initiative working group on marine genetic resources (MGR). Her publications (45 in total, seven as lead-author) span schistosomiasis, paragonimiasis, population genetics, deep-sea biodiversity studies, and aspects of marine policy. They have helped shaped interventions and policy, helping bridge the gap between scientific research and international policy frameworks.

## ABSTRACT

Ecosystems and biodiversity are under intense pressure from multiple cumulative anthropogenic pressures. At the same time, the burden of neglected tropical diseases (NTDs) continues to affect hundreds of millions of people globally. In the face of these current societal challenges, the need to generate, synthesise and utilise high quality biological data for science-based decision-making is more pressing than ever before. Data synthesis allows for the characterisation of ecosystems, monitoring of global change, leading towards evidence-based decision making and development of effective intervention strategies, whether relating to biodiversity and conservation or public health. However, knowledge gaps and barriers preventing the free flow of data can impede the incorporation of scientific findings into policy. These challenges are explored here through the lens of two contrasting fields of research, and drawing on six peer-reviewed publications by the author: 1) the NTDs schistosomiasis and paragonimiasis, addressing spatio-temporal trends in distribution and how findings can shed light on these diseases to support evidence-based interventions; and 2) studies of deep-sea biodiversity and marine genetic resources (MGRs), addressing key knowledge gaps in the context of global ocean governance frameworks. These different research fields provide a basis for exploring common elements (including to achieving effective science-policy integration), including the need for taxonomy and species-level data, the role of biorepositories and archiving, harmonisation efforts for data and sample pipelines, and effective communication and cooperation. Global networks can also act as intermediaries or translators across the science-policy nexus. Such organisations can provide the missing link between data and decision-making, and therefore advance science-policy as a co-produced endeavour. Here, commonalities in seemingly contrasting research fields provide insights for improved science-policy integration.

## LIST OF ACRONYMS

ABNJ: Areas Beyond National Jurisdiction  
AMSTH: The American Society of Tropical Medicine and Hygiene  
BBNJ: Biodiversity Beyond National Jurisdiction  
BSP: British Society for Parasitology  
CBD: Convention on Biological Diversity  
CCZ: Clarion Clipperton Zone  
COBRA: Crustal Ocean Biosphere Research Accelerator  
COR-NTD: Coalition for Operational Research on Neglected Tropical Diseases  
DSBS: Deep Sea Biology Society  
DSI: Digital Sequence Information  
DOSI: Deep Ocean Stewardship Initiative  
DOOS: Deep Ocean Observing Strategy  
EBVs: Essential Biodiversity Variables  
ESPEN: Expanded Special Project for Elimination of Neglected Tropical Diseases  
FAIR: Findable, Accessible, Interoperable, Reusable  
GBD: Global Burden of Diseases  
GBF: Global Biodiversity Framework  
GBIF: Global Biodiversity Information Facility  
GGBN: Global Genome Biodiversity Network  
GNTD: Global Neglected Tropical Disease Database  
GSA: Global Schistosomiasis Alliance  
INSDC: International Nucleotide Sequence Collaboration  
ISA: International Seabed Authority  
ISNTD: International Society for NTDs  
GSC: Genomic Standards Consortium  
MGR: Marine Genetic Resources  
NHCs: Natural History Collections  
NNN: Neglected Tropical Disease NGO Network  
NTDs: Neglected Tropical Diseases  
OBIS: Ocean biodiversity Information System  
PIP: Pandemic Influenza Preparedness framework  
SBI: BBNJ standardised batch identifier (referenced in the BBNJ Agreement)  
SDGs: Sustainable Development Goals  
R&D: Research and Development  
RSTMH: Royal Society for Tropical Medicine and Hygiene  
TDWG: Biodiversity Information Standards  
UKFCDO: UK Foreign and Commonwealth Development Office  
UNCLOS: UN Convention on the Law of the Sea  
WHO: World Health Organisation  
WIDP: WHO Integrated Data Platform  
WoRMS: World Register of Marine Species  
WoRDSS: World Register of Deep Sea Species

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# 1. INTRODUCTION

## 1.1 Societal challenges

Globally, biodiversity is in dramatic decline throughout marine, freshwater and terrestrial environments, resulting from multiple anthropogenic impacts (UNFCCC, 2021; Crona et al., 2021; Le Bris & Levin, 2020; Chase et al., 2020). At the same time, human populations are experiencing global public health crises, including the unrelenting burden of neglected tropical diseases (NTDs; Bryson et al., 2020). These apparently unrelated challenges share commonalities. Evidence-based decision making, whether for biodiversity and conservation or public health, requires the generation, synthesis and incorporation of reliable data into policy generation and implementation (Hoban et al., 2022; Gadelha et al., 2020). However, gaps and barriers to the flow of biological data and findings into policy can impede this process. Barriers include: 1) the understanding of what data are needed and where those data are, or can be obtained; 2) the delivery of data in a form accessible to policy makers; 3) non-standardisation of data when collected, and failure to understand the user needs in a policy framework, both in the design of databases and data collection; 4) insufficient capacity to collect (and digitise) data; and 5) insufficient capacity to generate novel data, e.g. identifications, species descriptions, biological, ecological and distributional data. Through a series of research papers published by the author, this thesis explores these impediments to science-based policy implementation, and potential solutions.

## 1.2 Aim of the thesis

The effectiveness of data influencing decision-making is discussed through the lens of two distinct areas of research: 1) the parasitic diseases schistosomiasis (blood fluke) and paragonimiasis (lung fluke) in sub-Saharan Africa, addressing spatio-temporal trends in distribution and how findings can shed light on these diseases to support evidence-based interventions (section 1.5.1); and 2) studies of deep-sea biodiversity and marine genetic resources (MGRs), addressing key knowledge gaps in the context of global ocean governance frameworks (section 1.5.2).

The science-policy relationships of these two differing fields are examined here through common themes, including: (i) a focus on taxonomy, species-level data and molecular studies; (ii) the role of natural history collections and biorepositories, archiving and digitisation; (iii) spatial analysis of species distributions; (iv) data principles of FAIR (Findable, Accessible, Interoperable and Reusable; Wilkinson et al., 2016); v) synthesis and re-use of data and sample sets; (vi) the necessity of cooperation, networks and partnership

building; (vii) the wider context of global policy agreements and frameworks and (viii) an overall emphasis on how science informs policy.

The research fields of NTDs and deep-sea biodiversity can both be characterised as ‘data-poor’, with substantive global information gaps evident for deep-sea biodiversity and genetic resources (Zhivkopoulos et al., 2024), and similarly for NTDs (Bryson et al., 2020). Supported by six peer-reviewed articles published by the author between 2019 and 2025, this thesis aims to shed light on these data-poor fields and synthesise information to allow incorporation of findings into policy frameworks, whether biodiversity- or health- related. The next sections include an overview of what is needed for science-based policy (Section 1.3), followed by challenges (Section 1.4), background to the research topics (Section 1.5), relevant policy frameworks (Section 1.6), and lastly, the approach of the thesis (Section 1.7).

### **1.3 What is needed to facilitate evidence-based science policy?**

#### **1.3.1 Taxonomy, species-level data and molecular studies**

What information is needed to support informed decision making for the key global challenges of biodiversity loss and the impact of NTDs? Firstly, species-level data provide the baseline resolution to define the scope of the challenge (Kaiser et al., 2023). Taxonomy or systematics is the process of discovery and description of new species. Species identification of known species, and comparison between species is a separate but related process, not to be conflated with species description itself, but still an important part of taxonomic work. It allows for identified specimens to be placed into their systematic context or position within the tree of life. Taxonomy is the bedrock that subsequent studies, e.g., population genomics, ecology and evolution, are built upon (Engel et al., 2021; Glover et al., 2018). Once described, species can be identified, e.g., in environmental monitoring, and protected under conservation frameworks (Kaiser et al., 2023). Taxonomy and species identification are essential to understanding diseases, both in the accurate identification of pathogens and hosts, and delineating distributions. Relative to diseases, deep-sea environments are at an earlier stage of discovery and description, and ongoing improvement of biodiversity knowledge is a priority where so few species are known.

Genetic or genomic data allow for taxonomic work but also characterisation of diversity *within* species at the population level, and the connectivity of populations (Allendorf et al., 2010). Information on species diversity, abundance, distributions and dispersal potential have relevance for both biodiversity conservation, and assessment of disease. In a deep-sea

context, population connectivity studies are key to developing effective conservation measures, including design of networks of marine protected areas, and understanding potential impacts of human activities at regional scales (Taboada et al., 2018; Gollner et al., 2017). Population genomics also allows accurate characterisation of parasite ecology and evolution, and disease transmission (Platt et al., 2025), valuable information to support public health interventions.

### **1.3.2 Role of natural history collections, archiving and digitisation**

While primary or novel observations are often necessary, prior observations and analysis of existing source material (e.g., natural history collections and biorepositories) can be readily accessed and provide data not otherwise available. Such collections and genetic archives play a central role in taxonomy and genomic research via provision of curated libraries of reference material. Through consistent approaches to vouchering of samples and specimens, studies can be reproduced and expanded upon (Schindel & Cook, 2018; Angeles & Catap 2023; McCartney et al., 2023). Archiving reduces the need for resampling and also enables future use for applications and techniques yet to be developed (McCartney et al., 2023). Some habitats, including the deep sea, are particularly challenging and resource intensive to sample, making vouchering even more critical (Rogers et al., 2023; Glover et al., 2015). Natural history collections and datasets derived from them offer spatio-temporal snapshots of species and ecosystems, providing historical baselines pre-dating current anthropogenic impacts. Collections together with associated contextual data (locality, collection, environmental information<sup>1</sup>) can shed light on climate and environmental changes on species, the spread of invasive species, extinction risks and adaptive processes (Hedrick et al., 2020; Meineke et al., 2019; Lister et al., 2011). Collections both historical and recent with contextual data are therefore invaluable as biological records, and can help piece together a picture of ecosystems, species distributions and diversity over time.

In a public health context, collections of pathogens, parasites and hosts provide genetically diverse research material, allowing for longitudinal studies, and in-depth insights into disease transmission (Pennance et al., 2022a, b; Webster et al., 2020; Léger et al., 2020; Tian-Bi et al., 2019; Knopp et al., 2019, 2016, 2013). Repositories can be leveraged to study the effects of drug pressure on parasite populations and wider evolutionary processes (Platt et al., 2025, 2022; Berger et al., 2022, 2021; Emery et al., 2025). The Schistosomiasis Collection at the Natural History Museum (SCAN) has allowed for many such studies,

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<sup>1</sup> Not to be conflated with metadata, or data that describe a dataset, i.e. data about data (Stow et al., 2018).

including those cited here (Emery et al., 2012, 2025). Natural history collections connect human, wildlife and environmental health, needed in surveillance of emerging infectious diseases, including identification of zoonotic hosts (Colella et al., 2021; Thompson et al., 2021; Cook et al., 2020, Galbreath et al., 2019; Moratelli & Calisher, 2015). Holistic sampling allows for capturing of the full ecological picture: parasite, host and surrounding environmental conditions (Colella et al., 2021; Schindel & Cook, 2018). Collections therefore align with the One Health framework, a recognition of the interconnected nature of human, wildlife and environmental health, and the importance of zoonotic reservoirs and paths of transmission (Díaz et al., 2023; Coker et al., 2011; see also Section 1.6.3).

Museums worldwide are now digitising collections at scale, allowing access to morphology/trait, molecular, spatial and contextual data for a range of applications, including those detailed above (Smith et al., 2022; Thessen et al., 2019). In digitisation, a key concept is that of the ‘digital extended specimen’, a dynamic or updatable digital representation of a physical museum object, which can be linked to related data sources, including genomic sequences, environmental data, imagery, scans, taxonomic identifications and geospatial data (Hardisty et al., 2022). This approach can convert a physically isolated collection into useable information. The global movement of digitisation and greater accessibility of natural history collections supports ‘democratising’ of these invaluable resources (Johnson et al., 2023; Sikes et al., 2022; Bakker et al., 2020).

The digitisation movement has seen the expansion of usage, and emergence of new techniques and methods. Molecular collections of tissue and DNA in museums and biobanks have enabled the recent explosion in genomics studies; and datasets derived from collections have also been extensively applied in species niche modelling (Schindel & Cook, 2018). New techniques have unlocked collections for additional applications, including environmental DNA (Harrison et al., 2019), and ‘museomics’ or utilising historical collections with ancient DNA techniques (Lund et al., 2022, Johnson et al., 2023; Sikes et al., 2022; Hahn et al., 2022). Another recent trend is the usage of machine learning for image/text processing for various applications including trait mapping and analysis (Johnson et al., 2023). Altogether, collections and research interact with, and inform the other, for example, in methods development and setting priorities for collection expansion (Hahn et al., 2022; Schindel & Cook, 2018).

### 1.3.3. Role of science networks and partnerships

To be effective, digitisation of natural history collections requires cooperation between institutions and networks at national and international levels (Lister et al., 2011). This digitisation movement has seen the development and expansion of global biological data networks and aggregators, including the Ocean Biodiversity Information System (OBIS<sup>2</sup>, 2025); the World Register of Marine Species (WoRMS<sup>3</sup>; Vandeputte et al., 2024); the Global Biodiversity Information Facility (GBIF<sup>4</sup>, 2025) and the Global Genome Biodiversity Network (GGBN<sup>5</sup>; Droege et al., 2014). Further, global programmes to undertake genomic sampling in standardised ways are now underway, such as Earth Biogenomes (Lewin et al., 2022) which aims to provide high quality genomes representative of biodiversity globally. With the rapid recent expansion of global-scale genomics programmes and digitisation efforts, networks for development of best practices and harmonisation efforts are increasingly important. Standards are needed to ensure comparability of datasets, or agreement on meaning of terms for describing data (Vogt, 2013). For broad-scale genomic sampling, standardised approaches in the collection, processing and storage of samples ensure genomic quality, sample consistency and comparability of resulting datasets (Sunagawa et al., 2020; Lewin et al., 2022). This need for community-led standards and best practice in biological data and sample sharing has seen the emergence of relevant networks, for example Biodiversity Information Standards (TDWG<sup>6</sup>) which oversees development of the biodiversity data standard Darwin Core (Wieczorek et al., 2012), and the Genomic Standards Consortium (GSC) which oversees genomic data standards (Field et al., 2011).

Health-specific platforms and partnerships include the WHO Integrated Data Platform (WIDP), and specifically for NTDs, the Global Neglected Tropical Disease Database (GNTD) which provides NTD data including health outcomes, and the Expanded Special Project for Elimination of Neglected Tropical Diseases ESPEN Collect, a WHO platform and data collection tool to help address meeting NTD health goals (see also section 1.5.1). Broader science networks beyond data platforms include the Global Schistosomiasis Alliance (GSA) and the International Society for NTDs (ISNTD).

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<sup>2</sup> <https://obis.org>

<sup>3</sup> <https://www.marinespecies.org>

<sup>4</sup> <https://www.gbif.org>

<sup>5</sup> [https://www.ggbn.org/ggbn\\_portal/](https://www.ggbn.org/ggbn_portal/)

<sup>6</sup> <https://www.tdwg.org>

#### **1.4 Challenges to incorporating science into policy**

Given the scale and pace of environmental change and resulting impacts on species abundance, distributions and richness, robust decision making is ever more urgent (Levin et al., 2019; Díaz et al. 2019; Elahi et al., 2015; McCauley et al., 2015). Recent studies emphasise the necessity of co-production by scientists and policymakers of knowledge that is both scientifically sound and policy-relevant (Latour & van Laerhoven, 2024; Cvitanovic et al., 2024; Turnhout et al., 2016). A challenge in establishing this collaborative approach is the quality and accessibility of scientific data and findings for non-specialists, including policymakers (Hogg, 2024; Hoban et al., 2022). Information gaps and blocks in the flow of data can impede the incorporation of scientific findings into policy. Biodiversity data are often stored in inconsistent formats, and don't always meet criteria of FAIR (Gadelha et al., 2021; Hoban et al., 2022; Weatherdon et al., 2017). A major barrier to the free flow of information into policy is a lack of data standardisation or harmonisation, impeding data synthesis (Gadelha et al., 2021). This is also a question of 'translation' or repackaging data for policy (Turnhout et al., 2016). Data are rarely synthesised or packaged in a way that is 'policy-ready' for easy digestion by decision-makers (Leonelli, 2019). Data synthesis in and of itself can be a missing element, presenting another barrier (Durden, 2025).

There are numerous contributing factors. Firstly, considering taxonomy and baseline species-level data as first principles, inadequate standardisation of taxonomic information has been a long-standing issue in biology (Grenié et al., 2021; Horton et al., 2024, 2017). Recently there has been considerable expansion in temporary or informal species names, those allocated to a species prior to a formal description, categorised as 'open nomenclature' (Horton et al., 2024, 2021; Sigovini et al., 2016). Such names can proliferate further if the same undescribed species is allocated a different name to an existing one published in a paper or database, given there is currently no formalised system or standardisation for usage.

There are several reasons for this development, a key one being a scarcity of taxonomists (Mammola et al., 2023; Engel et al., 2021). Describing species is a time consuming and highly specialised endeavour, but one that is little acknowledged within science funding frameworks (Bouchet et al., 2023; Engel et al., 2021). Taxonomic research, despite its critical role, is frequently unfunded and often conducted by taxonomists on a voluntary basis (Engel et al., 2021). Even for the taxonomy of snails of human diseases, although relatively well characterised, expertise has still been lost (Shiff, 2017). This is a common story across taxonomic groups (Horton et al., 2024; Engel et al., 2021). This has contributed to an exponential rise in the publication of sequence data without reference to voucher specimens

or solely-sequence based identifications (Sayers et al., 2025; Page, 2016). This recent explosion in temporary names has significant implications for accuracy of biodiversity assessments and therefore conservation and environmental policy (Horton et al., 2024).

A related challenge is that biological repositories/natural history collections are highly heterogeneous by nature, in contrast to clinical biobanks for example which focus on a small number of sample types from humans and which have a high degree of standardisation of sampling, processing and storage techniques, often incorporating high throughput automated workflows (Angeles et al., 2023; Ongarello et al., 2022; Collins et al., 2020; Nussbeck et al., 2016; Emery et al., 2025). The high variability of natural history collections produces considerable challenges in standardisation of methods of digitisation, curation, lab work and analysis. This brings associated costs and impacts for taxonomic output and data publication. Further, despite being a core element of biodiversity – and health infrastructure, natural history collections often have insufficient funding for maintenance, let alone development (Colella et al., 2021; Cook et al., 2020; Suarez et al., 2004). Long term funding to maintain and expand biorepositories is a major problem reported even for human clinical biobanks (Rao et al., 2019).

Another contributing factor is the complexity and size of genomic datasets (Taylor et al., 2017). The generation of genomic data is becoming increasingly accessible, with a vast reduction in sequencing costs and increasing availability of tools for analysis, with exponential growth in genomic data as a result (Lund et al., 2022). These data however are often little understood by non-specialists, and rarely incorporated into decision making frameworks, whether for biodiversity or health (Lund et al., 2022). Differing views on genetic metrics and how to best assess the diversity and adaptive potential of populations have also impacted on genetic data being fully incorporated into policy (Hogg, 2024; Hoban et al., 2022). Consequently, there is a broad scale disconnect between genomic data and applications in conservation and environmental management. Reference genomes are as important to public health as biodiversity conservation (Hoban et al., 2022; Schindel & Cook, 2018). In a public health context, although great advances have been made with the human genome (Hogg, 2024), similar challenges to biodiversity research are at play for neglected diseases, and complicated further by research inequities in sub-Saharan Africa (Fatumo et al., 2022; Lund et al., 2022).

These complexities are reflected in a heterogeneous biological data landscape, with varying degrees of data integration and exchange (Feng et al., 2022; Gadelha et al., 2021; Bingham et al., 2017). This landscape is populated by a multitude of databases, some highly

specialised, e.g. by taxon such as Fishbase<sup>7</sup>, and others broad, global data aggregators, e.g., OBIS. They often specialise by data type however, e.g. WoRMS houses taxonomic information for marine species; the International Nucleotide Sequence Database Collaboration (INSDC), genetic/genomic sequence data; and OBIS and GBIF, biodiversity occurrences (and environmental data), often derived from natural history collections. While global data standards such as Darwin Core allow for data interoperability and exchange between databases and infrastructures (Wieczorek et al., 2012), adoption and uptake can be variable (Gadelha et al., 2021). The databases also tend to ‘cluster’, for example INSDC and genetic databases form one distinct cluster, and biodiversity databases another, with the latter well integrated to the former (e.g. links of OBIS and WoRMS with INSDC), but less so vice versa. Usage of persistent stable unique identifiers is key to database interoperability and making data FAIR (Islam et al., 2023; Juty et al., 2020) and, therefore, a key element of good data practice (Page, 2023, Humphries et al., 2021; Jaspars et al., 2021). Identifiers associated with biological records however are not always persistent, compromising data exchange and contributing to duplication (Feng et al., 2022; Güntsch et al., 2017; Guralnick et al., 2015, 2014).

Nevertheless, the ecosystem of biodiversity data is still relatively cohesive and discoverable, primarily due to the scale of databases like GBIF and OBIS that aggregate data from multiple sources using pre-existing standards. While disease data can also be incorporated into GBIF for example (e.g. occurrences of parasites/hosts), there are no real equivalents to such databases in health<sup>8</sup>. Examples of existing platforms specifically for health data include WIDP, GNTD and ESPEN as above, and disease-specific genetic databases like WormBase ParaSite<sup>9</sup>, but the health data landscape is more fragmented overall. As an added complication, much of the NTD and wider health-data discourse is concerned with ethics and privacy given the consideration of patient confidentiality (Johnson & Parker, 2020; Nussbeck et al., 2016). This can impede the open sharing of patient data, even if fully anonymised (Tarwid et al., 2024). During the COVID pandemic, global collaborations and networks<sup>10</sup> were established for rapid vaccine development, a massive advances for both health data and sample sharing, but evidence of gaps (e.g. in patient information) persist (Boby et al., 2023; Van Noorden, 2021; Moodley et al., 2021; Paul & Chatterjee, 2020). At a fundamental level, there are indications of public health surveillance and research data failing to inform policy (Chiolero et al., 2023).

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<sup>7</sup> <https://fishbase.se/search.php>

<sup>8</sup> <https://www.healthdata.org/research-analysis/gbd?>

<sup>9</sup> <https://parasite.wormbase.org/index.html>

<sup>10</sup> <https://dndi.org/research-development/portfolio/covid-moonshot/>.

In combination, these challenges can further hamper effective use of biological data in decision-making, whether for biodiversity or public health (Colella et al., 2021; Bakker et al., 2020). These factors and others can impede incorporation of biological data into policy development frameworks, resulting in a gap between the state of knowledge in a research field and the design and implementation of policy (Knight et al., 2008).

## **1.5 Key research fields: background and knowledge gaps**

### **1.5.1 The NTDs schistosomiasis and paragonimiasis**

Schistosomiasis and paragonimiasis are diseases caused by trematodes (flatworm parasites), which affect millions of people globally. Both parasites have complex lifecycles involving one or more intermediate hosts with maturation occurring in the definitive host (humans and other mammals). Snails act as first intermediate hosts, but for schistosomiasis, knowledge gaps on their distribution and infection patterns persist, with implications for tackling this disease (Allan et al., 2020; Shiff, 2017). For African paragonimiasis, the snail host remains undiscovered, making it the only human parasitic disease without a fully known life cycle (Blair, 2024).

Human schistosomiasis, one of the most significant NTDs, is a major public health problem, with an estimated 250 million people affected and 700 million at risk (Vos et al., 2017). Schistosomiasis is caused by schistosome blood parasites. Uniquely among trematodes, schistosomes shed larval stages (cercariae) via infected freshwater intermediate snail hosts that are capable of directly infecting the mammalian host (through the skin). Schistosomiasis has a global distribution mostly in the tropics and sub tropics, encompassing South America, the Caribbean, Africa, the Middle East and Southeast Asia (Zhang & Ming, 2024). Most of the disease burden is found in sub-Saharan Africa, however, where the most widespread human schistosome infection is urogenital schistosomiasis, caused by *Schistosoma haematobium* (Bilharz, 1852), followed by intestinal schistosomiasis, caused by *S. mansoni* (Sambon, 1907).

Accurate species-level identification of the snail hosts and schistosome cercariae, and trends in their distribution and abundance over spatiotemporal scales are key to understanding transmission, and ultimately to inform treatment. The importance of snail studies cannot be overestimated as disease distribution directly reflects that of the snail host, in turn dependent on an array of environmental factors, including climate, topography, and

presence of aquatic vegetation (Perez-Saez et al., 2019, 2016; Kulinkina et al., 2018). Over the past few decades, field-based schistosomiasis research and intervention has focussed mainly on long-term drug treatment programmes with the anthelmintic praziquantel, rather than the intermediate host snails (Shiff, 2017). These programmes, however, have not had the effect anticipated (Lo et al., 2016), therefore interest and recognition of the role of the snail host has reemerged (Sokolow et al., 2018; Malishev & Civitello, 2020). Knowledge gaps on snail host diversity, distribution and infection persist, with significant implications for tackling this disease (Allan et al., 2020).

For the foodborne NTD paragonimiasis, also caused by trematodes, lack of information for intermediate hosts are even greater, particularly in Africa. Paragonimiasis has a broad, global distribution particularly in tropical regions, in Asia, the Americas, and Africa, and infects an estimated 23 million worldwide (Blair, 2024; Yoshida et al, 2019; WHO, 1995). Globally, most of the disease burden is found in southeast Asia. It is caused by trematodes of the genus *Paragonimus*, with a complex life cycle involving a snail first intermediate host, a decapod crustacean secondary intermediate host, and a mammalian definitive host. The picture is further complicated by the fact a broad range of hosts for the different parasite stages have been recorded (Blair, 2024; Voelker et al., 1975; Cumberlidge, 1999; Blair et al., 2001). Transmission to humans and other mammalian definitive hosts occurs by ingestion of raw or partially cooked freshwater crabs that harbour the infective larval stages of metacercariae (Blair, 2024). Over 50 species of *Paragonimus* are currently recognised, of which several have been reported to infect humans (Blair, 2024), including the species complex of *P. westermani* (Kerbert, 1878), *P. skrjabini* (Chen, 1959), *P. heterotremus* Chen & Hsia, 1964, *P. uterobilateralis* Voelker & Vogel, 1965, *Paragonimus africanus* Voelker & Vogel, 1965, *P. gondwanensis* Bayssade-Dufour et al., 2014, *P. kellicotti* Ward, 1908 and *P. mexicanus* Miyazaki & Ishii, 1968.

Paragonimiasis in Africa is the only human parasitic disease without a fully characterised life cycle, with the first snail hosts of the African species of *Paragonimus* unknown, and the first life stages undescribed (Cumberlidge et al., 2018). In terms of global research effort, paragonimiasis in Africa has received remarkably little attention, for example compared to Asia, where it is more of a public health issue (Blair, 2024). Recent reports of significant transmission are evident however within endemic regions in southeast Nigeria and Southwest Cameroon (Iboh et al., 2018; Eze, 2015; Uttah et al., 2013; Moyou-Somo et al., 2014). For *Paragonimus* globally, taxonomy is ill defined and in need of revision (Blair, 2024). For African *Paragonimus* in particular, almost no molecular work has been

undertaken on the four known species, and potential undescribed diversity has been noted in the literature (Aka et al., 2009, 2008).

In terms of distribution, spatial mapping and modelling allows for identification of foci of infection, particular geographic localisations of high infection. Spatial characterisation of such foci, often termed “hotspots” in schistosomiasis, is crucial to understand transmission (Kittur et al., 2019, 2017). The importance of spatial characterisation of distribution and modelling of potential distributions is even greater in little studied diseases like paragonimiasis, precisely because of the massive knowledge gaps on distribution, and the complex life cycle which means paragonimiasis requires a highly specific ecology to support overlapping distribution of all hosts.

### **1.5.2 Deep-sea biodiversity and marine genetic resources**

The deep sea represents the largest environment on earth, but the least known, where most species remain unknown to science (Appeltans et al., 2012; Poore et al., 2015; Higgs & Attrill, 2015; Horton et al., 2021). Deep-sea biodiversity supports a vast reservoir of MGR potentially of great benefit to society, with applications ranging from climate change mitigation, biomimetics and new medicines (Barbosa et al., 2020; Tortorella et al., 2018; Sigwart et al., 2021; Blasiak et al., 2022). For example, in marine microbes, a group identified to have great potential as genetic resources, recent studies reveal previously unreported levels of biodiversity and novel function, with many potential applications (Chen et al., 2024, Vohsen et al., 2024; Schubotz, 2024; Berdy, 2005).

The deep ocean, however, is under threat of unprecedented biomass and biodiversity loss from multiple past, present, and future cumulative anthropogenic pressures (Le Bris & Levin, 2020; Crona et al., 2021). These pressures include impacts from deep-sea fisheries, oil and gas activities, pollution including tailings disposal, and climate change, in particular deoxygenation and acidification (Levin et al., 2019). Considerable policy discussion has focussed on the potential impacts of future seabed mining, the effects of which on ecosystems are very little understood (Levin et al., 2020; Simon-Lledó et al., 2019a; Gollner et al., 2017; Lagabrielle et al., 2014). There is the potential impact of the exploration of MGR itself, for example harvesting of species to provide the raw biological materials for a product if the bioactive compound cannot be synthesised, e.g. in the case of the New Zealand sponge *Lissodendoryx* sp. for the anti-tumor compound halichondrin B, where synthesis challenges persist (Dissanayake et al., 2024). However, such cases are rare as synthesis of MGR is usually possible (Krusberg et al., 2024). Further, such a production scenario is most unlikely be sustainable or feasible, which would certainly be the case for most deep-sea

species. In the first instance, there is the impact of collection of biological samples, but this is generally relatively minimal, and carried out with ethical guidelines (Hope et al., 2018) with the specific purpose of better understanding these unknown environments.

## **1.6 Global policy agreements and frameworks for deep sea biodiversity, MGR, and health**

In response to the need for global efforts to progress conservation of biodiversity and public health, specific agreements and commitments have developed, mainly under the auspices of the UN, and often after decades of negotiations. Discussed here are three global instruments, the International Seabed Authority established in 1994 which oversees activities on the seabed beyond national jurisdiction (the 'Area'), the Biodiversity Beyond National Jurisdiction (BBNJ) Agreement, adopted in 2023 for areas beyond national jurisdiction, and the World Health Organisation, mandated to support global public health, established under the UN in 1948. Details of these policy frameworks relevant in the context of the thesis are outlined below.

### **1.6.1 The BBNJ Agreement and the Convention on Biological Diversity**

In the face of the global biodiversity crisis (Díaz et al. 2019; McCauley et al., 2015), which now extends to the deep sea, the text for a new global agreement for biodiversity beyond national jurisdiction (BBNJ) was adopted in 2023, after almost two decades of negotiations (UNGA, 2023)<sup>11</sup>. It will enter into force after 60 States have ratified it (as of July 2025, ratified by 50 states and the European Union<sup>12</sup>). The treaty is intended to address gaps in ocean governance in areas beyond national jurisdiction (ABNJ), and questions of equity and benefit sharing in the exploration of MGRs. It has four substantive elements – Part II (MGR, including the fair and equitable sharing of benefits), Part III (Area Based Management Tools, including Marine Protected Areas), Part IV (Environmental Impact Assessment) and Part V (Capacity Building and the Transfer of Marine Technology).

Although many modalities of benefit sharing of MGR are yet to be established (Humphries, 2025), the overarching objective of Part II of the BBNJ Agreement is the conservation and sustainable use of MGR. Here, the necessary first step is to know what a species is, the baseline for further studies (i.e. taxonomy, as above). Embedded also within the BBNJ agreement is the recognition of the role of collections, in the need for future proofing and

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<sup>11</sup> Agreement under the United Nations Convention on the Law of the Sea on the Conservation and Sustainable Use of Marine Biological Diversity of Areas Beyond National Jurisdiction under the UN General Assembly (UNGA), 2023).

<sup>12</sup> 16<sup>th</sup> July 2025

biobanking of samples (Article 11, 12). Good scientific practice and FAIR data and samples are both guiding principles and literal requirements of the agreement (Article 14). This aligns with the principles of Open Science, or accessible, transparent sharing of data, samples and methods (Gallagher et al., 2020). A central element of the MGR provisions of the Agreement is the BBNJ standardised batch identifier (SBI hereafter), a requirement for a structured persistent identifier at the level of a research cruise (or equivalent collecting event), which accompanies all subsequent MGR collections and associated data from a given cruise throughout the research and development lifecycle (Article 12). This is to support transparency and traceability of MGR including any potential commercialisation (i.e. development of a product) back to the point of origin (see section 5.1.1). The SBI would be issued by the Clearing House Mechanism, a centralised open access platform yet to be established under the Agreement.

Within national jurisdictions, MGR (and other genetic resources, e.g. terrestrial, freshwater) are covered by the Convention on Biological Diversity (CBD)<sup>13</sup>, in most cases under the Nagoya Protocol. Both the BBNJ Agreement and the CBD emphasise the fair and equitable sharing of benefits of genetic resources and associated sequence data, termed Digital Sequence Information (DSI) under the frameworks (Sett et al., 2024). Existing challenges to the free exchange of genetic samples and data under some national implementations of access and benefit sharing) regulations (Prathapan et al., 2018; Laird et al., 2020) have led to concerted attempts to resolve this issue in CBD and BBNJ fora (Sett et al., 2024; Aubry et al., 2022; Scholz et al., 2022). These agreements both stress the importance of capacity building, of which access and benefit sharing of genetic resources and DSI are essential components. Note hereafter the term capacity sharing is used, in contrast to the terminology of capacity building from both frameworks. This is to better reflect the reality of knowledge exchange and North-South collaborations (Guilhon et al., 2025). The emphasis under the CBD's agreement on DSI, and the BBNJ Agreement on capacity sharing to generate, handle and use DSI, provides the policy backing necessary to improve collaboration and harmonise capacity-sharing efforts across frameworks.

### **1.6.2 The International Seabed Authority**

The BBNJ Agreement (not yet in force) is the third and most recent implementing agreement under the United Nations Convention of the Law of the Sea (UNCLOS), 1982. The International Seabed Authority (ISA), established in 1994 under UNCLOS, regulates, inter

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<sup>13</sup> <https://www.cbd.int>

alia, the exploration and potential future exploitation of mineral resources on the seabed<sup>14</sup>. Most mineral exploration is currently focussed on polymetallic nodules composed of cobalt, manganese, nickel and other metals, which occur on some abyssal plain regions, but two other mineral types are also under exploration, cobalt rich manganese crusts (generally similar in metal composition to nodules), and polymetallic sulphides associated with hydrothermal vents at mid-ocean ridges. Initial interest and exploration for deep-sea minerals dates back several decades to the 1960s and 1970s, but slowed in the early 1980s with waning metal prices and demand (Jones et al., 2017), technical challenges, and lack of a regulatory framework discouraging further investment (Glasby, 2000; Scott, 2001). Recent years have seen increased attention on metals such as cobalt and nickel, primarily driven by narratives for projected demand for the electric battery production market (Herrington et al., 2021, Royal Society, 2017). Recent analysis has found this to be largely speculative, based on misrepresentations of current mineral shortages, supply chains and market dynamics (Alger et al., 2025). Both the initial interest in deep-sea mineral exploration and the more recent increase in contract area applications from 2010 - 2015 were driven mainly by the higher than normal commodity prices of the time (Ardrón, 2020).

The largest area of mineral exploration is the Central Pacific's Clarion Clipperton Zone (CCZ), which being the main area of activity and therefore scientific exploration, is the focus for this section of the thesis. This vast area of seabed stretches areas beyond national jurisdiction between the exclusive economic zones of Mexico and Kiribati (approx. 6 million km<sup>2</sup>). The CCZ is currently subject to 17 mineral exploration contracts, covering an area of approx. 1.3 million km<sup>2</sup>. The region has a heterogeneous habitat (Simon-Lledó et al., 2019b) but is largely abyssal sedimented plains with extensive cover of polymetallic nodules. High diversities of benthic invertebrate fauna have been recorded in abyssal sedimented habitats (Hessler & Sanders, 1967).

Discussions on transparency and benefit sharing of MGRs are somewhat mirrored in the ISA negotiations on regulation for the exploitation of deep-sea mineral resources, and, like the BBNJ negotiations, debates have been hampered by substantial knowledge gaps, and questions on data availability (Ardrón et al., 2018, Horton et al., in review). Biological baseline surveys are required by the ISA for mineral exploration activities, to support decision making, including for any future mining (Ardrón et al., 2018). There has been a historical lack of (access to) biological and taxonomic studies in the CCZ however, despite mineral exploration cruises dating back decades (Smith et al., 2019; Jones et al., 2017). A

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<sup>14</sup> UNCLOS, Article 156

key consideration for the CCZ, especially given the possibility of future mining activities, is the robust application of biodiversity data in environmental policy. It is the responsibility of the ISA to make baseline biological datasets from mining exploration activities available, and to this end, the public database 'DeepData' was launched in 2019<sup>15</sup>. Given the potential for the database to be utilised as a key decision-making tool by the regulator (Ardron et al., 2018), it could directly affect environmental decision making in the area. This makes assessment of the FAIRness of DeepData, both as a platform and of the data it contains particularly pertinent to future decision making (Durden, 2025).

### **1.6.3 Health frameworks and global commitments for both biodiversity and health**

Commitments to biodiversity and health are outlined in specific global frameworks, for example the Sustainable Development Goals (SDGs; for improving equality and health outcomes by 2030 (Hák et al., 2016); and the Kunming-Montreal Global Biodiversity Framework (GBF), which aims to address biodiversity loss by 2030, maintain genetic diversity of species and support benefit sharing for genetic resources (Nunez-Vega et al., 2025).

Global policy frameworks for health primarily fall under the umbrella of The World Health Organization (WHO). The frameworks for NTDs aim to reduce disease burden, enhance healthcare access, and strengthen surveillance. For example, the WHO Roadmap for NTDs (2021–2030) aims for a 90% reduction in people needing interventions, the elimination of at least one NTD in 100 countries, and improved health system integration. The Sustainable Development Goals calls to end NTDs, expand universal health coverage, and advance disease research (SDG 3.3). These commitments are part of a coordinated global effort toward NTD elimination, improved healthcare equity, and strengthened health infrastructure. The Pandemic Influenza Preparedness (PIP) Framework has been established by the WHO to improve global access to vaccines, diagnostics, and treatments for influenza pandemics. While not specific to NTDs it is relevant here in terms of key aims: improved collaboration between governments, industry, and public health institutions, and an emphasis on rapid and effective data and sample sharing. Also relevant is that WHO and related frameworks endorse the interdisciplinary concept of One Health, which places health in a wider context of wildlife, environment, humans and disease (see e.g. Díaz et al., 2023;).

How to advance commitments for health and biodiversity and measure progress is an ongoing question, and efforts are underway for increased and meaningful quantification

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<sup>15</sup> <https://data.isa.org.jm/isa/map>

(Nunez-Vega et al., 2025). A goal of GBF, for example, is to maintain genetic diversity and ensure effective population sizes to maintain adaptive potential to environmental change. Biodiversity can encompass many different elements beyond species richness, including genetic, ecosystem or landscape diversity (Hoban et al., 2022). Indicators are structured biological or physical metrics for incorporation into policy frameworks (Durden, 2025). Biological indicators specifically for genomic and genetic information are currently being developed to monitor global genomic biodiversity as part of the Essential Biodiversity Variables or EBVs (Hoban et al., 2022) and provide a means to measure and report against for global frameworks, like GBF. Another relevant indicator framework is that of the Essential Ocean Variables, or EOVs (Muller-Karger et al., 2018). In health, the World Health Statistics reports published by WHO use indicators from the SDGs, giving consistency to measuring progress over time<sup>16</sup>.

For commitments on sharing of capacity and benefits, at a granular level, data standards for access and benefit sharing permits have been developed under the umbrella of GGBN and others (Schiller et al., 2024; Droege et al., 2014), and a new indicator specifically for benefit sharing under GBF (Nunez-Vega et al., 2025). Ringfencing open access and harmonising approaches to benefit sharing for DSI under different UN frameworks is a necessary step especially given these data are often combined in analysis, e.g. DSI that fall under CBD, BBNJ or other frameworks (Sett et al., 2024). It is equally important to align objectives for capacity sharing, especially given the policy backing from both BBNJ and CBD (see also Section 1.6.1).

The BBNJ agreement calls for usage of the best available science (Article 7). Extensive community engagement is needed for broad consultation on what this constitutes, to ensure a representative range of science, and geographies are covered (Pearson, 2024, Cologna et al., 2025). In the BBNJ agreement, ‘major programmes’ in the context of MGR research are referenced (Article 12). Such programmes could include global-scale sampling initiatives in the vein of Earth Biogenomes (Lewin et al., 2022), e.g. the Ocean Genome Atlas Project (Laiolo et al., 2024, see also Blasiak et al., 2021, 2020), Tara Oceans (Sunagawa et al., 2020; Pesant et al., 2015), and others. There is the potential to further leverage efforts for global research cooperation through the BBNJ Agreement, helping to progress key conservation commitments.

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<sup>16</sup> <https://www.who.int/publications/i/item/9789240094703>

## 1.7 An interdisciplinary approach

There is growing recognition that planetary health and human health are interlinked (Ebi et al., 2020; Demaio et al., 2015), for example through the One Health concept and awareness of interconnection of biodiversity loss, habitat modification and disease risk (Díaz et al., 2023; Glidden et al., 2021; Keesing & Ostfield, 2021; Keesing et al., 2006). Despite this, planetary and human health are often viewed as separate concerns and siloed as distinct research fields. Moreover, a lack of interdisciplinary approaches and isolation of disciplines overall has been identified as a barrier in effective integration of science and policy (Matzek, et al., 2014; Hogg, 2024; Kaiser & Gluckman, 2025).

Interdisciplinary approaches however can lead to new insights and breakthroughs (Ebi et al., 2020), progress science-policy engagement and facilitate consultation of all relevant stakeholders (Durden et al., 2025). An interdisciplinary approach is exemplified in this work through the interweaving of common themes, and drawing connections and parallels, to provide insight across different research fields (NTDs and deep-sea biodiversity/MGRs). MGR-related research is inherently interdisciplinary, encompassing fields as diverse as taxonomy, oceanography, ecology, microbiology, chemistry, molecular biology, economics, and social science, lending itself to interdisciplinary approaches. NTD studies are also interdisciplinary, encompassing different fields including epidemiology and operational research, parasitology, population genetics and ecology (Colella et al., 2021). There are commonalities between the research topics. Research on MGRs is generally highly applied, seeking solutions to societal problems, including public health, with much exploration of MGRs focussed on potential medicines (Francesch et al., 2024; Sigwart et al., 2021). It is also closely linked to policy, e.g., frameworks for benefit sharing and capacity sharing (Harden-Davies et al., 2022). Much research into NTDs focusses on societal applications of improving disease interventions (Deol et al., 2019), and is similarly concerned with policy input, questions of benefit sharing, knowledge exchange and equity in research particularly given most of the disease burden is in the Global South, but most related research activity in the Global North (Lund et al., 2022; Emery et al., in 2025).

The collected work in this thesis aims to integrate differing fields of research to highlight commonalities, focus on policy impact and provide a path forward to new ways of envisaging global societal challenges (Figure 1). The common theme that runs through the chapters of the thesis is the gathering of large raw, primary and secondary datasets, including sample and metadata, strategies of validation and quality control, building of FAIR datasets and their analysis to produce science evidence in a format useable for policy makers.

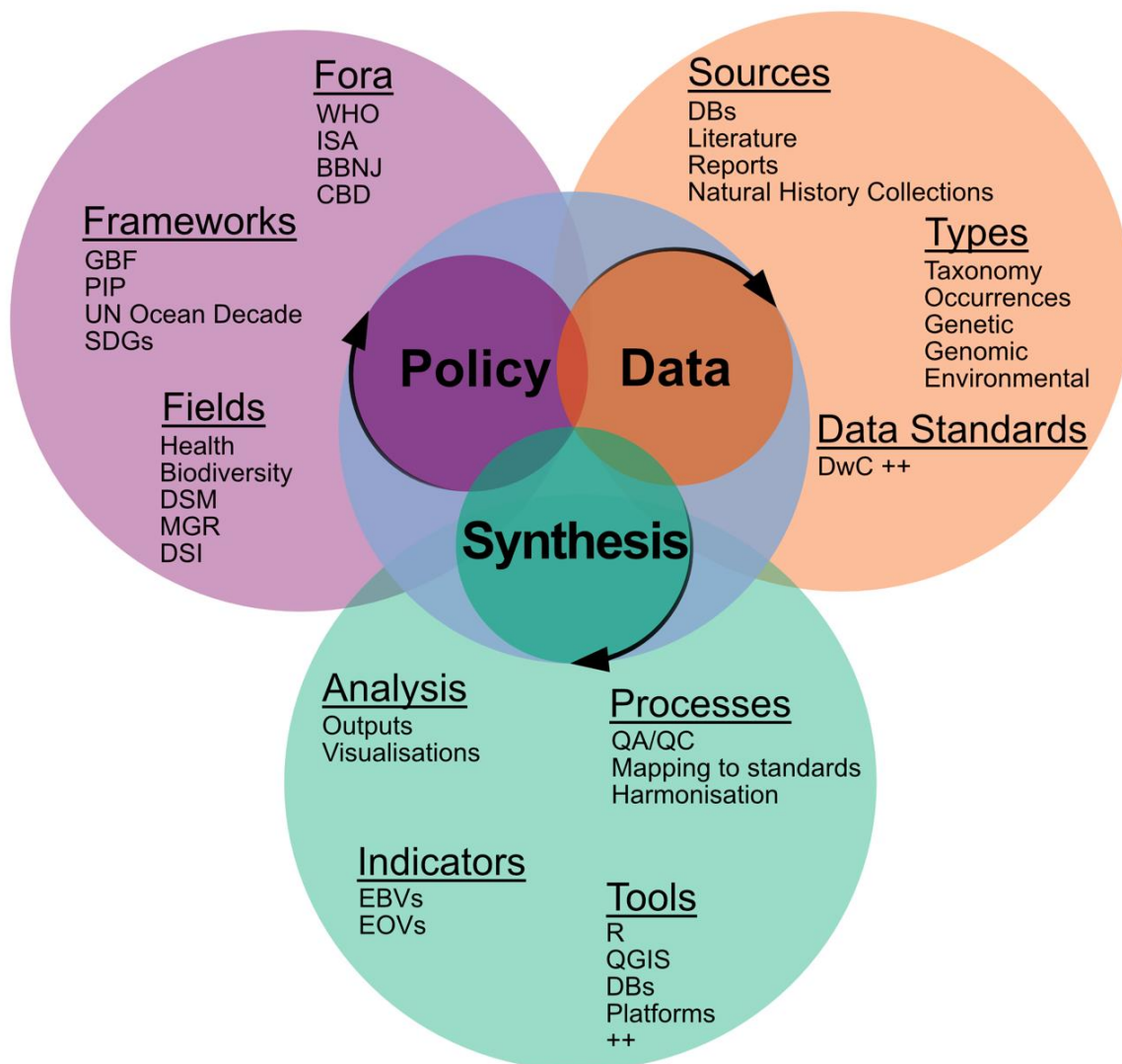


**Figure 1:** Overview of approach - data to synthesis to policy, or how data (of different categories, e.g., taxonomy, genomic) and from different sources (literature, databases, etc), are processed, standardised or harmonised and synthesised for policy. Many elements overlap, e.g., indicators serve as a data product and may be embedded into a policy framework. (Note this framework is not intended as a comprehensive overview but rather highlighting some key elements discussed in this thesis).

## 2. METHODS SYNTHESIS

### 2.1. Overview

An overview of the main methodologies common to the presented research outputs is provided here, with full detail on specific methods provided in the published works themselves. Primary data (original data collection) and secondary data (existing, published datasets) were both utilised in this thesis. The first presented publication utilises primary data, covering five years of monthly snail surveys (Rabone et al., 2019a). Other publications utilise secondary data to produce novel findings (Rabone et al., 2021, 2019b, 2023a; 2023b). Most research outputs presented therefore involved analysis and synthesis of secondary data, large-scale multi-year, multi-decadal datasets. These datasets were all assembled for analysis (see next section).

**Table 1:** List of presented research outputs

| Section | Publication          | Research Area | Category     | Data source |
|---------|----------------------|---------------|--------------|-------------|
| 3.1     | Rabone et al., 2019a | Disease/NTDs  | publication  | Primary     |
| 3.2     | Rabone et al., 2021  | Disease/NTDs  | publication  | Secondary   |
| 3.3     | Rabone et al., 2019b | Deep-sea/MGR  | publication  | Secondary   |
| 3.4     | Rabone et al., 2023a | Deep-sea/MGR  | publication  | Secondary   |
| 3.5     | Rabone et al., 2023b | Deep-sea/MGR  | publication  | Secondary   |
| 3.6     | Rabone et al., 2025a | Deep-sea/MGR  | book chapter | N/A         |

### 2.2. Data compilation and literature reviews

Considering the first step of sourcing and assembly of the raw data, for the study analysing primary data (Rabone et al., 2019a; section 3.1), the primary datasets were collated from longitudinal multi-year field datasets in Excel and R (R Core Team, 2024). The data were originally either in paper forms, in which case they were digitised, or excel files, in which case, combined, data headings standardised, and in some cases, cross referenced with physical collection (specimen) labels at NHM where needed. Data were stored in excel and in the NHM KE-Emu database, a content management system for biological collections data.

The presented publications reviewing literature included both a general literature review (Rabone et al., 2019b) and two systematic reviews (Rabone et al., 2021; Rabone et al., 2023a), the former following the established standard of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria (Moher et al., 2009). This method involves specific steps and criteria to allow for a structured and repeatable systematic review (see Rabone et al., 2021).

For studies utilising secondary sources, data were sourced and compiled from the literature and from databases, either through direct downloads on web portals or application programming interface (API) calls in R (Rabone et al., 2021; Rabone et al., 2019b; Rabone et al., 2023a; Rabone et al., 2023b). For data sourced from the literature, this involved a digitisation step for extracting data e.g. from within text-tables, and/or retrieving supplementary tables (Rabone et al., 2023a; 2021). For data sourced from databases, the original raw downloads were archived, and edits were made on a copy. For the two studies conducting a systematic review, occurrence data were extracted, digitised, compiled and georeferenced, i.e., an occurrence dataset was generated from the literature (see Rabone et al., 2021; Rabone et al., 2023a).

### **2.3. Data processing**

Given the use of secondary data, most of the presented publications relied on mixed data sources i.e., combining data from different databases and sources, often across years and decades. Data QA/QC processes were developed for consolidation of diverse data, involving harmonisation of variable datasets and formats, consistent with community standards, e.g. data mapped to global data standards like Darwin Core. The first step of data compilation involved combining and harmonising datasets in Excel and R, e.g., standardising variable names and data columns. This was also necessary in the presented publication analysing primary data (Rabone et al., 2019a). The data for the two systematic reviews, whether the paragonimiasis, or the CCZ work, crossed many different study types, survey methods and time periods. As far as possible, column headings were harmonised and data were separated onto different tables by type, e.g. site information, or epidemiological data (Rabone et al., 2023a; 2021).

### **2.4. Data analysis**

#### **2.4.1 Statistical methods and models**

Analysis was preceded by an extensive literature search to ascertain the best fit of analysis method to the data (e.g., Rabone et al., 2019a, Rabone et al., 2023a). Statistical models were chosen based on suitability for the dataset in question, and the goal of the research. For example, in Rabone et al., 2019a, variations in snail counts were analysed with generalised linear mixed effects models, and model testing was performed with DHARMA (Hartig, 2016). Model selection/simplification was not performed because of issues noted in the literature (Burnham et al., 2011; Mundry et al., 2011). Similarly, tests for zero inflation were not performed based on assessment of the data and the literature. For publications assessing biodiversity, different metrics were utilised to allow comparison between them. For

example, in Rabone et al. (2023a), species richness metrics included incidence-based estimates, Chao2 (Chao et al., 2014; Chao, 1987), and abundance-based estimates, Chao1 and the Abundance-based Coverage Estimator (ACE, Chao & Chiu, 2016; Ugland & Gray, 2004; Cowell & Coddington, 1994), conducted in the R packages *vegan* (Oksanen et al., 2018) and *iNEXT* (Hsieh et al., 2016).

#### **2.4.2 Mapping and spatial analysis**

Mapping for visualisation of species occurrences was undertaken in QGIS and R (Rabone et al., 2021, 2023a). The quantification and visualisation and variability of sampling effort were also conducted in these programmes (Rabone et al., 2021; Rabone et al., 2019b; Rabone et al., 2023a). For example, in Rabone et al., 2023a, a broad assessment of CCZ-wide sampling effort was conducted in QGIS to visualise data gaps. To derive a measure of pseudo-effort, the area was randomly subdivided into grids using the ‘*raster*’ package (Hijmans, 2022), and geographical points for sampling locations intersected with the grids using the ‘*spatialEco*’ package (Evans, 2021). Here, pseudo-effort was quantified as the total number of sampling sites located in a given grid square, as a proxy of sampling intensity.

#### **2.4.3 Adapted approaches**

Methodological approaches were developed through the works, tailored to the research question/approach, for some of the presented publications. This followed a thorough literature search as a baseline. For example, in Rabone et al. (2023a), estimates of species diversity were made by comparing proportions of undescribed to described species, both for the whole dataset, and for a subset of literature to account for factors like potential misidentification. Estimates were compared to global marine species diversity estimates, given none specifically for deep-sea species were available. Total recorded species on WoRMS were compared to the global marine species estimate of Mora et al. (2011), which was assessed to be the best available from reviewing the literature. The parallel study, the technical assessment of the DeepData database (Rabone et al., 2023b) did not follow an established methodology, given none were available as such works are rare, but methods were developed based on a database user perspective, and also to support the aims of the parallel study to conduct a biodiversity assessment of the region (Rabone et al., 2023a). The latter ensured the methods were addressing the research utility of the database and the data it contained. The methods were aligned with community standards by assessing FAIRness of the database (Rabone et al., 2023b).

## 2.5. Data publication

Generation and provision of summary as well as raw data is an important element of the methodology of several works (see Table 1 in Rabone et al., 2023a, and Table 1 in Rabone et al., 2021). Where datasets were not generated, equivalent summary data was provided (see Table 1 in Rabone et al., 2019b). All works are consistent with the principles of Open Science and FAIR, published in open access journals, and code and datasets generated were archived and made available. The latter represents a key element of the methods and the works as a whole in four of the presented publications (Rabone et al., 2019a, 2021, 2023a, 2023b), especially given the datasets were often of a substantial scale, e.g., >100,000 records in Rabone et al. (2023a). Part of this study is also available as an online checklist of all metazoan taxa from the area that meets criteria of FAIR (Rabone et al., 2025b; <https://www.marinespecies.org/deepsea/CCZ/>).

## 3. SYNOPSES OF PUBLICATIONS

**Table 3:** List of author contributions for the presented research outputs

| Section | Publication          | Contribution                                                                                                                                                                                                                       |
|---------|----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 3.1     | Rabone et al., 2019a | MER curated samples collected for the study, compiled the resulting datasets, co-designed and conducted data analysis, produced first draft and led the drafting, editing and manuscript production throughout.                    |
| 3.2     | Rabone et al., 2021  | MER conceptualised the study, conducted the data analysis, created the figures, and led the writing and editing of the manuscript.                                                                                                 |
| 3.3     | Rabone et al., 2019b | MER co-conceptualised the study, conducted data curation, formal analysis, investigation, methodology, and validation. Also, co-conducted visualization, wrote the original draft, and led writing–review and editing.             |
| 3.4     | Rabone et al., 2023a | MER co-conceptualised the study, collected and curated data, conducted the investigation and analysis, created figures, wrote the first draft of the manuscript and led the writing and editing process.                           |
| 3.5     | Rabone et al., 2023b | MER conceptualised the study and designed the methodology, curated data, conducted investigation and analysis, created figures, wrote the original draft and led the writing and editing of the manuscript.                        |
| 3.6     | Rabone et al., 2025a | MER contributed the key aim for the book chapter, co-conceptualised the approach, contributed to design of the use-cases, assisted with figure design and development, co-wrote the first draft and led editing of the manuscript. |

### 3.1 Publication 1: Rabone et al. (2019a)

Rabone, M., Wiethase, J.H., Allan, F., Gouvras, A.N., Pennance, T., Hamidou, A.A., Webster, B.L., Labbo, R., Emery, A.M., Garba, A.D. and Rollinson, D., 2019a. Freshwater snails of biomedical importance in the Niger River Valley: evidence of temporal and spatial patterns in abundance, distribution and infection with *Schistosoma* spp. *Parasites and Vectors*, 12, 1-20.

<https://doi.org/10.1186/s13071-019-3745-8>

PMID: 31640811

Knowledge of intermediate freshwater snail host distribution and abundance is crucial to understanding schistosomiasis disease transmission and informing effective intervention strategies. After a period of emphasis on long term praziquantel-based drug treatment programmes in schistosomiasis research (Shiff, 2017), there has been renewed interest and recognition of the importance of snail studies (Sokolow et al., 2018; Malishev & Civitello, 2020). This investigation of intermediate host freshwater snails in the Niger River Valley aimed to characterise any spatial and temporal patterns evident in abundance, distribution and infection with schistosomes causing human schistosomiasis. Snails collected included species of *Bulinus*, host of *S. haematobium*, *Bulinus truncatus* (Audouin, 1827), the main intermediate host in the region, *Bulinus globosus* (Morelet, 1866) and *B. forskalii* (Ehrenberg, 1831); and also host of *S. mansoni*, *Biomphalaria pfeifferi* (Krauss, 1848). Another freshwater snail species of biomedical importance was surveyed, *Radix natalensis* (Krauss, 1848), host of the human and veterinary disease fascioliasis. Seasonality in abundance was evident across all species, with significantly higher abundance in the dry season. Seasonality of infection was also observed for *B. truncatus*, the main intermediate host in the region. Seasonality of abundance is likely due to multiple abiotic factors working in concert in this setting, e.g., rapid water level rise in the rainy season, and associated temperature reduction and increased turbidity. Evidence of seasonality of infection has major implications for monitoring and interrupting transmission of schistosomiasis in the region, highlighting the importance of such work to inform current and future schistosomiasis intervention programmes. Evidence of seasonality of infection has major implications for monitoring and interrupting transmission of schistosomiasis in the region, highlighting the value of such studies to inform schistosomiasis intervention programmes. Here monthly surveys allowed the resolution needed to discern the pattern observed.

### 3.2 Publication 2: Rabone et al. (2021)

Rabone, M., Wiethase, J., Clark, P.F., Rollinson, D., Cumberlidge, N. and Emery, A.M., 2021. Endemicity of *Paragonimus* and paragonimiasis in Sub-Saharan Africa: A systematic review and mapping reveals stability of transmission in endemic foci for a multi-host parasite system. PLoS Neglected Tropical Diseases, 15(2), e0009120.  
<https://doi.org/10.1371/journal.pntd.0009120>  
PMID: 33544705

While little known, the NTD paragonimiasis is a global foodborne disease of significance, affecting an estimated 23 million people worldwide (Blair, 2024; Yoshida et al, 2019; WHO, 1995). Paragonimiasis has a broad, global distribution (Asia, Africa, the Americas), but most of the disease burden is found in southeast Asia (Blair, 2024). It is caused by the trematode *Paragonimus*, which has a complex life cycle involving a primary snail host, a secondary decapod crustacean host, and a mammalian definitive host. Paragonimiasis is primarily a lung disease, the main clinical symptoms often overlapping with tuberculosis, with resulting potential for diagnostic confusion (Blair, 2024; Nwokolo et al., 1972). This work is the first systematic review of paragonimiasis in Africa. The study highlighted significant prevalence and intensity in endemic foci in southeast Nigeria, including in recent studies. Significantly higher prevalence of *P. uterobilateralis*, and the potential endemicity of *P. africanus* in Cote d'Ivoire, previously unreported, were evident. The study found significantly variable prevalence and intensity of the key African species (*P. uterobilateralis* and *P. africanus*) across crab hosts, potentially due to differences in susceptibility. Mapping conducted as part of the study revealed temporal stability of transmission over decades in endemic foci and revealed evidence of broader transmission than that reported previously (Cumberlidge et al., 2018) with extensive under-sampling. The mapping showed a close association of *Paragonimus* distribution with rainforest zones, but also localised transmission at 'outlier' locations with suitable ecology for all hosts. This highlights that additional spatial analysis is necessary to better characterise potential distribution of paragonimiasis. Like the other studies (Rabone et al., 2019, 2023a) it highlights the need for molecular studies address key knowledge gaps and help to establish baseline knowledge. The study is topical in terms of growing interest in One Health and zoonoses (Díaz et al., 2023) and addresses the little recognised impact of African paragonimiasis both in terms of human health and as a wildlife disease of importance. The systematic review has attracted significant research attention from the research community as a result, leading to the establishment of new collaborations and projects.

### 3.3 Publication 3: Rabone et al. (2019b)

Rabone, M., Harden-Davies, H., Collins, J.E., Zajderman, S., Appeltans, W., Droege, G., Brandt, A., Pardo-Lopez, L., Dahlgren, T.G., Glover, A.G. and Horton, T., 2019b. Access to Marine Genetic Resources (MGR): raising awareness of best-practice through a new agreement for Biodiversity Beyond National Jurisdiction (BBNJ). *Frontiers in Marine Science*, 6, 520.  
<https://doi.org/10.3389/fmars.2019.00520>

Access to marine genetic resources (MGR), both samples and related data, is key for deep-sea biodiversity research and an obligation under the BBNJ Agreement but is complicated by the fact such environments present significant collection challenges. In this presented publication, a review of current and best scientific practice in MGR research in ABNJ, these challenges and how they can be addressed in the BBNJ process are explored. The study aimed to 1) inform the development of the draft treaty text, under negotiation at the point of publication, and 2) highlight its importance for the science community, both for harmonising activities, and raising awareness for ethical considerations, e.g., readiness for the coming requirements including benefit sharing and capacity sharing. The work also presents an attempt to not define but to 'conceptualise' an MGR sample, to illustrate several points for policymakers, including: a) one to many relationships of any MGR sample to resulting subsamples; b) any physical sample collected may contain MGR, even if not intended to be used for MGR research; and c) the importance of avoiding an artificial separation of samples and data, e.g. MGR and associated digital sequence information (DSI), given the two are distinct but interlinked entities. These points highlight the complex realities of the research process to policymakers. The article discusses emerging norms of best practice, and how these can be encouraged under the treaty process, highlighting the importance of networks and collaboration. Specific policy recommendations are provided to support the development of the draft treaty text, including the importance of funder recognition of taxonomy and the role of museums, requirements to archive deep-sea samples in national collections, commitment to FAIR data and samples, and a global cruise registry. This work achieved notable impact in the BBNJ negotiations, with several of its recommendations being incorporated into the final treaty text.

### 3.4 Publication 4: Rabone et al. (2023a)

Rabone, M., Wiethase, J.H., Simon-Lledó, E., Emery, A.M., Jones, D.O., Dahlgren, T.G., Bribiesca-Contreras, G., Wiklund, H., Horton, T. and Glover, A.G., 2023a. How many metazoan species live in the world's largest mineral exploration region? *Current Biology*, 33, 1-14.

<https://doi.org/10.1016/j.cub.2023.04.052>

PMID: 37236182

Baseline biodiversity knowledge of the Central Pacific's CCZ is crucial to effective environmental management of a region subject to deep sea mining exploration. A key first step is the creation of a curated checklist of known taxa and estimates of numbers of undescribed species present. To determine the current state of knowledge of benthic metazoan biodiversity in this active mineral exploration zone, a first comprehensive synthesis of published data in literature and databases was conducted, representing >100,000 records from seven data sources. This publication also delivered the first checklist for the region, which comprises 433 named species of benthic metazoa, including 185 described from the CCZ itself, and over 5000 species with informal names potentially new to science. Rapid recent growth in taxonomic efforts for the CCZ was evident. The proportion of undescribed species was estimated as 88–92%. These estimates are similar to the proportion of known species recorded at the time of the study in WoRMS, versus the global marine species estimate of Mora et al. (2011) at 89% (241,129/2.2M). In estimates of total species richness, sampling of the CCZ appears far from complete, as evident in the rarefaction and species accumulations curves. Total species richness estimates ranged from >6,000 to >8,000 (Chao 1,2, ACE, Jackknife). Since taxonomic uncertainty is lower at a higher taxonomic rank, with less likelihood of misidentifications, diversity at family level was also examined. The family accumulation and rarefaction curves approached asymptote, with an estimated total family richness of 469 total (+/18 SE) for Chao1 and 544 total (+/24 SE) for Chao2. These estimates could be compared with the checklist total of 501 families, showing Chao1 to be an underestimate, and Chao2 a feasible estimate given it can be compared against the checklist, with a total of 501 families. Species richness estimates overall are likely to increase as the data improve. It is important to recognise the uncertainties of biodiversity knowledge in the region, with clear implications for environmental management, but also the need for such syntheses, checklists, and fundamental taxonomic work to iteratively improve knowledge. This work has highlighted both the scale of the diversity, and the biological unknowns in the region at a critical juncture in the ISA negotiations on mineral exploitation.

### 3.5 Publication 5: Rabone et al. (2023b)

Rabone, M., Horton, T., Jones, D.O.B., Simon-Lledó, E. and Glover, A.G., 2023b. A review of the International Seabed Authority database DeepData from a biological perspective: challenges and opportunities in the UN Ocean Decade. Database, 2023, baad013. <https://doi.org/10.1093/database/baad013>

Environmental baseline surveys and monitoring are required by the ISA for any seabed mineral exploration activities. It is the responsibility of this regulator to collate and make available data provided by contractors conducting surveys as well as to accumulate data from research projects carried out in the region. The ISA recognised the need to create a database of geological and environmental/biological data in 2002 and to make the latter publicly available (ISBA/8/C/6). Subsequently the public database 'DeepData' was launched in 2019. In recent times, DeepData began publishing sizable quantities of records (>50,000 at the time of the study), with associated records available on global databases such as OBIS, INSDC and WoRMS. This study is the first analysis of DeepData, including of the biological data holdings for the most active area of seabed mining exploration (the CCZ). This work conducted a general technical assessment of the database, covering whether the biological data and platform meet criteria of FAIR. A comparison was made of equivalent data available on OBIS via the ISA regional node, operational since June 2021<sup>17</sup>. General suitability of the database as a tool for environmental decision-making was also evaluated, and recommendations made for its development into the future. Within the database, there was evidence of wholesale duplication of datasets, a lack of standardisation of taxonomic information and an absence of unique record identifiers, all compromising downstream data handling. Comparison of datasets on DeepData versus those on OBIS revealed significant issues with data mapping from the ISA data templates to Darwin Core prior to data harvesting by OBIS, with the result of inconsistent datasets across the platforms. Overall, the study revealed fragilities in the ISA data system, but also positive developments, including adoption of common data standards and new collaborations with global databases and networks, OBIS and WoRMS. The findings on duplication, identifiers and data quality are significant given their potential impact on environmental decision making related to seabed mining regulations, and the role of DeepData as an environmental decision-making tool by the regulator. Concluding remarks address the importance of FAIR and accessibility of data portals for policy and decision-making beyond the context of the ISA environmental regulations, e.g. the UN Ocean Decade (Claudet et al., 2020) and the SDGs. Some of the recommendations have since been implemented by the ISA, directly contributing to improved data management for the data platform.

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<sup>17</sup> <https://obis.org/node/9d2d95be-32eb-4d81-8911-32cb8bc641c8>

### 3.6 Publication 6 Rabone et al. (2025)

Rabone, M., Horton, T., Humphries, F., Lyal, C.H., Muraki Gottlieb, H., Scholz, A.H., Vanagt, T. and Jaspars, M., 2025. BBNJ Agreement: Considerations for Scientists and Commercial End Users of MGR at Research, Development and Commercialization Stages. In: Humphries, F., (ed) Decoding Marine Genetic Resource Governance Under the BBNJ Agreement. Sustainable Development Goals Series. pp. 283-315. Springer, Cham. [https://doi.org/10.1007/978-3-031-72100-7\\_14](https://doi.org/10.1007/978-3-031-72100-7_14)

This book chapter is part of a volume analysing the BBNJ Agreement, adopted by consensus in September 2023 after almost two decades of negotiations. The BBNJ Agreement is intended to address gaps in ocean governance and answer questions on equity and benefit sharing of MGR collected from ABNJ. This presented publication provides science perspectives on Part II of the agreement, the MGR provisions. It (1) investigates how current scientific practice is supported or challenged by elements of the requirements; (2) provides considerations for those conducting MGR research and development (R&D) across sectors (e.g., academia and industry); and (3) identifies areas needing input by the scientific community. This is discussed through real world examples, referencing MGR-related research in the UK as a case study, and scenarios based on existing applications of MGR which follow the pathway of a collected sample through the research process and beyond to potential commercialisation. These scenarios cover a representative range of activities and utilisation, and address areas of complexity. They start with a simple example of a research cruise on a national vessel conducting biodiversity/biodiscovery research in ABNJ, provided with contextual information on current practice pertaining to cruise planning, operations and reporting. Later, scenarios are expanded to more complex, non-linear applications of MGR and associated DSI. The scenarios provide a platform to explore how requirements could play out in practice, including those relating to data infrastructure, for example the SBI, which is equivalent to a cruise identifier in current usage, and data management plans. The work provides an overview of the MGR R&D process in entirety, highlights consistency of treaty requirements with current practice, addresses areas for improvement and potential challenges for compliance, and explores opportunities for increased harmonisation, to support practitioners and ultimately the implementation process. It highlights overall: 1) the importance of good scientific practice and data as FAIR, including how this can be fed into the BBNJ process; 2) the importance of collaboration, stakeholder engagement and dialogue between scientists and policymakers in the ratification process and beyond; and 3) the need for harmonisation across UN fora in approaches to benefit sharing for DSI and capacity sharing to be effective. The work has achieved direct policy impact through usage by the UK government during drafting of domestic BBNJ legislation.

## 4. RESEARCH IMPACTS

### 4.1 Impact of the published works

The presented research progresses over time through analysis of large-scale multi-year datasets to syntheses, reviews and commentary, including specific policy recommendations. They move from focus on primary datasets for example (Rabone et al., 2019a), to synthesis of large-scale multi-year, multi-decade and multi-source data sets (Rabone et al., 2021, Rabone et al., 2023a; Rabone et al., 2023b) to wider commentary, including exploration and development of practical scenarios for how policy frameworks may be implemented (Rabone et al., 2025a). Impact of the works is elaborated upon below, in order of the presented publications (3.1-3.6).

As a body of work, the presented research outputs demonstrate notable impact. In terms of subsequent citation rates, they average 15 per year per publication (Table 2). The selected works have achieved impacts at a variety of scales and in different disciplines and contexts. For example, the deep-sea works (Rabone et al., 2019b, 2023a, b, 2025) have garnered significant global media attention in the context of both the formation of the new BBNJ Agreement and the ongoing deep-sea mining negotiations at the ISA. In contrast, the work on paragonimiasis for example (Rabone et al., 2021) is very much a starting point given the state of research in the area, but influential and notable in terms of contributions to academic network development. Therefore, while varying in terms of scale and context, all works have achieved demonstrable impact – in science and policy.

**Table 2:** Citations of presented publications, as recorded on the 19<sup>th</sup> July, 2025

| No. | Publication          | Research Area              | Citation         | By year* <sup>1</sup> |
|-----|----------------------|----------------------------|------------------|-----------------------|
| 3.1 | Rabone et al., 2019a | Disease/NTDs               | 66               | 11                    |
| 3.2 | Rabone et al., 2021  | Disease/NTDs               | 21               | 5                     |
| 3.3 | Rabone et al., 2019b | Deep-sea/MGR               | 89               | 15                    |
| 3.4 | Rabone et al., 2023a | Deep-sea/MGR               | 63               | 32                    |
| 3.5 | Rabone et al., 2023b | Deep-sea/MGR               | 25* <sup>2</sup> | 13                    |
| 3.6 | Rabone et al., 2025a | Deep-sea/MGR               | 16               | 16                    |
|     |                      |                            | <b>280</b>       |                       |
|     |                      | Other papers* <sup>3</sup> | <b>1412</b>      |                       |
|     |                      | Total citations            | <b>1692</b>      |                       |

\*<sup>1</sup> Citation rate averaged by year

\*<sup>2</sup> Includes two citations of pre-print

\*<sup>3</sup> 45 publications in total

#### **4.1.1 Neglected tropical disease publications**

Rabone et al. (2019a) examines freshwater snail hosts of schistosome parasites in the Niger River Valley, finding evidence of seasonality of infection with major implications for monitoring and interrupting transmission of schistosomiasis in the region. Examining this study in the context of the wider literature, few recent equivalent snail studies have been published (but see Manyangadze et al., 2021; Wood et al., 2019; Gouvras et al., 2017), showing the value of the Schistosomiasis Consortium of Operational Research (SCORE) programme to developing an evidence base to inform control efforts based on interrupting transmission (Colley et al., 2020). A parallel study, Pennance et al. (2020), contributes the molecular characterisation of the snail host and schistosome species.

The results on seasonality in abundance are consistent with published literature, both from Niger and from similar Sahelian environments, and also markedly different climates (Gouvras et al, 2017; Perez-Saez et al., 2016; Dabo et al., 2015; Labbo et al., 2008). The findings on seasonality of schistosome infection prevalence in snail hosts are rare, however. Here, careful monthly surveys provide the fine-scale temporal resolution needed to discern the pattern observed. In terms of wider impacts and outreach, the study has been used for teaching in a biomedical science undergraduate course at Cardiff University as an example of outstanding work on schistosomiasis (Tammy Horton, National Oceanography Centre, pers. comm.).

In publication 2 (Rabone et al., 2021), the first systematic review and geographic mapping of paragonimiasis in Africa was conducted, to help address the extensive knowledge gaps and update the true public health significance of the disease (Cumberlidge et al., 2018; Appleton, 2014; Mazigo et al., 2013). The work illustrates what can be achieved purely through analysis of existing literature without access to primary data; and the necessity of reviewing the body of literature in its entirety to capture the full picture. As a synthesis of current knowledge and mapping of endemic foci, the study expands significantly on earlier works (Aka et al., 2008; Cumberlidge et al., 2018). It illustrates the need for taxonomy and molecular studies to establish baseline knowledge, consistent with the other presented publications (Rabone et al., 2019a & b, 2023a). Little to no spatial characterisation of paragonimiasis in Africa (or indeed elsewhere) had been done previously. Mapping is essential, however, for highly focal diseases like paragonimiasis or schistosomiasis to identify endemic foci and better understand transmission in these areas (Kittur et al., 2019). Occurrence of paragonimiasis depends on specific ecology that can support overlapping distribution of all hosts. Spatial analysis is especially relevant in paragonimiasis, given the

parasite's complex life cycle with multiple hosts, to identify where the right conditions for these life stages overlap.

This presented publication is topical in terms of growing interest in One Health (Díaz et al., 2023). A key part of the work's impact has been to illuminate the current state of the disease, including as a wildlife disease of importance, which has been little explored in the literature (Friant et al., 2015). The study highlighted significant prevalence and intensity in endemic foci in southeast Nigeria, including recent studies published in African journals which had not received global research attention (e.g. Iboh, 2018; Uttah et al., 2013).

Moreover, the work has generated significant interest and helped galvanise researchers in the field, including new partnerships with multiple institutes, including: the WHO Department of Tropical Diseases, the University of Abidjan, Centre de Recherches Médicale de Lambaréné (CERMEL), the University of Brescia, the Bernhard Nocht Institute for Tropical Medicine, the University of Douala, Adekunle Ajasin University, James Cook University and the University Hospitals of Tübingen and Heidelberg. These partnerships have led to joint grant applications, co-authored research papers published and in review (Aka et al., 2023; Aka et al., in review; Marchese et al., in preparation), and a joint programme of fieldwork in Gabon, conducted in partnership with CERMEL and University of Heidelberg in February 2025. One of the works in review is a publication with WHO providing treatment recommendations for areas co-endemic for both schistosomiasis and paragonimiasis (Marchese et al., in preparation). Through compilation of existing data, the publication represents a valuable dataset and basis for additional work, including spatial modelling (Rabone et al., in prep) and has re-energised work in the field.

#### **4.1.2 Deep-sea biodiversity publications**

The presented publication of Rabone et al. (2019b) has been a synthesis of major global impact, with ideas developed in the work that were later incorporated into the BBNJ Agreement. Its impact is evidenced in a consistent rate of citations (82 over six years). It provides key recommendations for development of the draft treaty text, which proved to be highly influential, provided at a critical juncture during the development of the treaty. The work was also distilled into a policy brief<sup>18</sup>, widely read and circulated by state delegates, and quoted on the floor of the negotiations (Arianna Broggiato, European Commission, pers. comm.). That the work was influential at this crucial phase is evident from the text of the

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<sup>18</sup> <https://doi.org/10.13140/RG.2.2.23660.41608>

treaty itself. The emphasis on current scientific good practice and FAIR is directly referenced in the text (Article 14), similarly, requirements for archiving of deep-sea samples (in Article 12). The concept of a centralised cruise registry is directly incorporated in the treaty text through requirements for notification, and the role of the Clearing House Mechanism as a centralised and open access platform, including maintaining a centralised list of cruises (Articles 12; 16). The work also provides an attempt to describe (rather than 'define') MGR as a broader concept, referenced in subsequent discussions and articles (Humphries et al., 2020). Within the published literature, the study is novel, mapping the existing data landscape relevant to deep-sea research and in relation to the BBNJ Agreement, and capacity-sharing needs. It also includes provision of key summary data, relevant databases, data standards and data tools, with few equivalent works (but see Bingham et al., 2017).

This work addresses the importance of persistent identifiers in science and specifically their role in transparency of MGR, a key issue in the negotiations (Humphries et al., 2021). MGR have long proved a sticking point for reaching consensus (Oldham & Thambisetty, 2023). Concerns have been raised on one hand of potential lack of transparency in the event of any commercialisation, with developing states seeking assurances for equitable monetary benefit sharing. On the other hand, this contrasts with concerns about an expensive and cumbersome system of tracing MGR (i.e., track and trace) that could hamper science and R&D in general for likely minimal chances of monetary benefits, given most biotechnology largely targets terrestrial or inshore organisms (Leary & Juniper, 2013; Scholz et al., 2022). Observers have noted that this emphasis on monetary value can divert focus from the tangible and realisable non-monetary benefits of sharing data, samples, and knowledge, key elements of capacity sharing (Harden-Davies & Snelgrove, 2020; Leary & Juniper, 2013). Rabone et al. (2019b) was used during the negotiations to highlight persistent identifiers and how they operate in practice in relation to MGR traceability. As the draft text developed, identifiers came to play a key role in the MGR provisions of the treaty as a solution for this long-standing MGR 'conundrum' (Oldham & Thambisetty, 2023).

The presented publication of Rabone et al. (2023a) is the first comprehensive synthesis of metazoan biodiversity from the CCZ. Building on previous studies (Smith et al., 2019), it provides the first estimates of both the known and unknown species richness across the region. There is uncertainty in these estimates, but as a synthesis of the published data, they represent a starting point to be improved upon as additional data and new statistical approaches become available. Within the wider deep-sea literature, the study represents an unusual biodiversity assessment of a deep-sea region. This also means, however, there is a lack of comparable data, which presents an ongoing challenge to contextualise the CCZ

within a global picture of deep-sea biodiversity, highlighting the lack of studies like these. A key development is the creation of a curated checklist of known taxa, providing a baseline for iterative development of biodiversity knowledge, improving identifications, reducing uncertainty and supporting future taxonomic tools, including field guides for the region. Improved knowledge of biodiversity is key to environmental management in the CCZ, especially given the potential for future mining activities (Amon et al., 2022; Durden et al., 2017). This work has already accrued 46 citations within two years (Table 1).

Wider impact includes science communication and outreach, as the study featured in hundreds of press articles in global media outlets in multiple languages (online, print, TV, e.g., the Guardian, CBC, Washington Post, Nat Geo, Le Monde, ABC and many others). It featured on BBC's Inside Science top five science stories of 2023, and continues to be cited in the press, for example as the focus of a prominent article published in the Guardian in March 2025<sup>19</sup>. The work not only achieved broad scale public exposure, but was also timely, published at a pivotal point in the ISA mineral exploitation regulation negotiations, with the anticipation of the first exploitation license proposed by The Metals Company. It highlighted both the scale and significance of the biodiversity of the region, and the vast unknowns, and given the level of attention and temporal overlap, it potentially contributed to the increase in states calling for a moratorium on deep sea mining from mid 2023 to the present, with 37 at the time of writing<sup>20</sup>.

The parallel study of Rabone et al., 2023b provides the first technical assessment of both the ISA database itself and its biological data holdings, in contrast to the current literature, where recent reviews survey the biodiversity data landscape as a whole (Feng et al., 2022; Gadelha et al., 2021; König et al., 2019; Bingham et al., 2017) or focus on specific issues inherent in biodiversity informatics, e.g. taxonomic data (Horton et al., 2021). Crucially, the extensive record duplication uncovered was found to significantly reduce diversity estimates in Rabone et al. (2023a). This underscores the importance of valid identifiers, and the policy relevance of FAIR data, as discussed in the other presented publications (Rabone et al., 2019b; Rabone et al., 2023b; Rabone et al., 2025a). Further, identifying problems within the database at this stage of its development is a critical contribution, preventing early mistakes becoming a systemic problem.

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<sup>19</sup> <https://www.theguardian.com/environment/ng-interactive/2025/mar/12/as-countries-scramble-for-minerals-the-seabed-beckons-will-mining-it-be-a-disaster-visual-explainer>

<sup>20</sup> 18<sup>th</sup> July, 2025

In addition, this work has achieved direct policy impact through its recommendations, which have been directly addressed by the ISA data management team, some already implemented and several in planning stage, ascertained both by direct communication from the ISA secretariat, and follow-up usage of the database. These changes have improved accessibility; for example, biological data are no longer separated by type of collecting method on the database, reducing data processing steps by users (<https://data.isa.org.jm/isa/map/>). Critically there is the possibility for DeepData to be used as an environmental decision-making tool for a nascent potential industry. With a dramatic turn of events in April 2025, a US executive order<sup>21</sup> at first glance undermined the authority of the ISA, provoking an international outcry further underscoring the need for global cooperation and data sharing<sup>22,23</sup>. Recent legal commentary argues the US has not demonstrated sufficient objections to UNCLOS historically to justify it being circumvented under US law and therefore the US executive order is unlikely to lead to deep sea mining in ABNJ (Willaert, 2025). Aside from how the situation may develop, there is an urgent need to ensure that biological datasets contained in the database are accessible and FAIR to support stakeholder engagement, third-party analysis, and effective decision-making. Together with the parallel study (Rabone et al., 2023a), the work has provided a major contribution towards deep-seabed mining environmental policy.

The final presented publication (Rabone et al., 2025a) was motivated in part by recognition of gaps in awareness and engagement by the science community regarding the Nagoya Protocol requirements under the CBD (Prathapan et al., 2018); and by the need for lessons learned from this process. This work examines the MGR provisions of the BBNJ treaty, providing a novel and important contribution to the literature by addressing the role of science in the BBNJ process and providing recommendations. In providing considerations for policymakers, and at a critical phase, i.e. ahead of the first Conference of the Parties, it represents a timely work. It contributes a roadmap for MGR repositories/collections towards meeting the substantive requirements under the agreement, updating earlier publications, i.e. Rabone et al. (2019b), which provided recommendations during drafting phase as above, and the co-authored work of Collins et al. (2021). In the context of the wider literature, the presented publication contributes science perspectives to complement the existing body of BBNJ works, in large part with a legal focus (e.g. Gjerde et al., 2022; Humphries et al., 2020; Harden-Davies & Gjerde, 2019; Tiller et al., 2019). The presented publication also discusses

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<sup>21</sup> <https://www.whitehouse.gov/presidential-actions/2025/04/unleashing-americas-offshore-critical-minerals-and-resources/>

<sup>22</sup> <https://www.isa.org.jm/news/statement-on-the-us-executive-order-unleashing-americas-offshore-critical-minerals-and-resources/>

<sup>23</sup> <https://www.nytimes.com/2025/04/25/us/china-trump-seabed-mining-international-law.html>

how the treaty presents a linear vision of science (Lawson et al. 2024), which differs from the realities of research. Meaningful, iterative science-policy engagement and collaboration with relevant stakeholders during this phase is particularly important as states move towards ratification and implementation (Ardron et al., 2024; Blasiak & Jouffray, 2024).

In Rabone et al. (2025a), the need for an interdisciplinary perspective was recognised, a key issue for science-policy engagement (Matzek et al. 2014). Interdisciplinarity is reflected in the authorship of the work across both science and law. This presented publication has the potential to reach a broad audience across these fields. As the UK prepares domestic legislation ahead of ratification of the Agreement, the work has “been instrumental to the drafting lawyers and in constant use” (Lowri Griffiths, UKFCDO, pers. comm.). For additional evidence of impact, there are references to consultation with the Natural History Museum in the draft domestic legislation<sup>24</sup>. The publication also led to an invitation to co-lead Chapter 5 of the UN World Ocean Assessment, ‘use of genetic resources and biotechnology’ (Rabone et al., in review), a UN-led publication and process conducted on a five-year cycle which aims to provide evidence on marine ecosystems including changes to inform policy (Weatherdon et al., 2017). It has also led to a follow-up study in preparation and the creation and co-leadership of an interdisciplinary BBNJ working group, a collaboration of state delegates, researchers, and leads of global databases (OBIS, WoRMS, GBIF and INSDC), critical interdisciplinary work, helping a) to galvanise engagement across communities; and b) to ensure that the data infrastructure requirements of the treaty are fit for purpose, and embedded within existing systems.

#### **4.2 Additional publications in NTDs and deep-sea biodiversity**

The author has contributed numerous additional publications to those included as chapters in the thesis, 39 in total (Supplementary References 8.1). Contributions have also been made in the form of open access reports that have been peer reviewed (Rabone & Glover, 2023; Jaspars et al., 2021). Of the peer-reviewed publications additional to those presented here as chapters, 20 are in parasitology, primarily schistosomiasis, and 19, deep sea biodiversity or related BBNJ policy. The studies cover a diverse range, from population genomics in schistosomes (Platt et al., 2025; Landeryou et al., 2022), and operational and epidemiological research in schistosomiasis (Knopp et al., 2019, 2016; Léger et al., 2020), to integrative taxonomic works for deep-sea invertebrates (Drennan et al., 2025, 2021; Neal et al., 2023, 2022a, b; see Supplementary References 8.1 for all co-authored publications).

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<sup>24</sup> <https://www.gov.uk/government/publications/agreement-under-the-united-nations-convention-on-the-law-of-the-sea-on-the-conservation-and-sustainable-use-of-marine-biological-diversity-of-areas-be>

Published works not included as the presented research outputs demonstrate knowledge of molecular techniques. In the lead author work of Rabone et al. (2015) for example, population genetics knowledge is evident, from DNA extraction, PCR and sequencing to analysis of genetic data and interpretation. In publications as second author, contributions were made to the generation and analysis of genetic and genomic data (Landeryou et al., 2022; Webster et al., 2015; Wiklund et al., 2023). Given the focus on molecular studies in this thesis, these works are referenced here to demonstrate that the six presented publications are well grounded in knowledge of this field; and have also gone beyond primary analysis in several cases to interpret policy relevant to the handling of genomic data (Rabone et al., 2025a). Additional published works as co-author involved contributions to preparation, compilation and analysis for multi-year primary environmental and epidemiological datasets (Knopp et al., 2013, 2019; Gouvras et al., 2017) and conducting most of these steps for a snail survey primary dataset (Gouvras et al., 2017). Similarly, significant mapping contributions were made to other publications as a co-author, including extensive spatial characterisation of schistosomiasis prevalence and intensity (Knopp et al., 2019).

#### **4.3 Summary of impact**

In summary, the works included in the thesis have achieved major, measurable policy impact, in a BBNJ context, contributions of text and interpretations into the UK draft domestic BBNJ legislation, and the signature of policy recommendations in the treaty text itself, in the context of environmental regulations under the auspices of the ISA, directly improving and supporting biological data management by the regulator in the Area with implementation of recommendations for their database, and contributing to discussions on a precautionary pause on deep sea mining by ISA member states; and in a neglected tropical disease context, re-energising and galvanising a highly neglected research area of African paragonimiasis including establishment of research projects and networks and direct engagement with WHO.

## 5. DISCUSSION

### 5.1 Common themes – challenges and opportunities in science-policy

Working across the apparently disconnected research disciplines of parasitic disease and the deep sea has revealed numerous common themes (Table 3). These include the importance of taxonomy, natural history collections and archiving, data standardisation and FAIR data science principles, strong networks and interdisciplinary approaches, and capacity sharing; and how these can be advanced through global agreements and commitments (Rabone et al., 2019a & b, 2021, 2023a & b, 2025a). Research in both fields should provide an evidence base for management, intervention and priorities for further studies, but data consolidation, interpretation, and presentation in appropriate formats for policy makers is a common challenge (Figure 2). A focus on solutions (including provision of recommendations) is therefore a consistent part of the presented research outputs. Collectively, the presented publications provide a means to explore common themes across disciplines, with the aim of highlighting the importance of informed decision making, gaining insights from comparing deep-sea and NTD research spheres, and focussing on current challenges in science-policy integration.

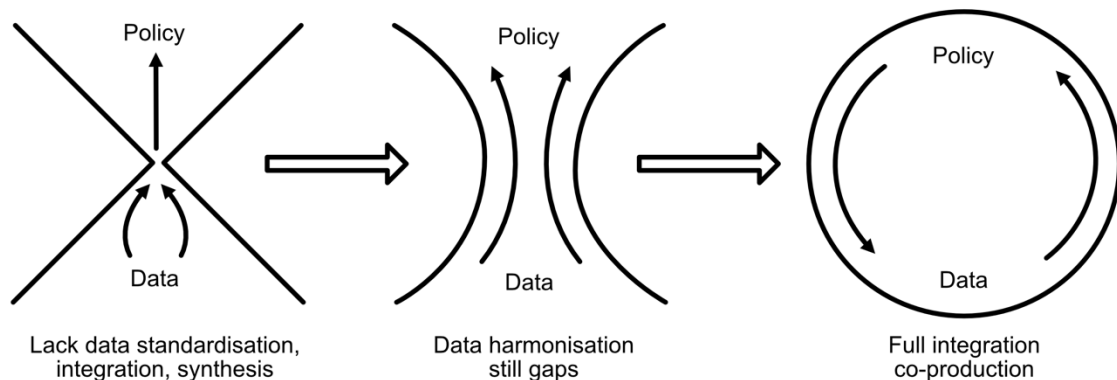


**Figure 2:** Conceptualised illustrations of different levels of science-policy integration. On the left, challenges with data integration, standardisation/harmonisation and synthesis result in a bottleneck. In the middle, more data and findings can flow into policy with improved exchange, but knowledge gaps and siloing of disciplines can impede some flow of data. On the right, an ideal scenario of full integration and co-production of science-policy (see Section 5.1.3).

### *Informatics case study 1: the CCZ*

Most of the works use data from mixed sources and formats, a key challenge in biology and biodiversity informatics (Durden et al., 2025; Gadelha et al., 2021). Standardised methods have been identified as a key element in policy relevance and ease of applicability of scientific findings into policy (Hoban et al., 2022; Weatherdon et al., 2017). Reproducible methods allow data users to trace back to the processes involved in data generation, particularly important if the data are utilised in decision making (Gadelha et al., 2021). Highly structured, standardised methods are evident in the presented publications (publication 3.4), and there are commonalities in methods across the works (see section 2).

Taxonomy underpins all the presented studies. For publication 3.1, a well-developed taxonomic framework allowed confident identification of the snails acting as the parasite intermediate host, so that their distribution could be understood. Publication 3.2 illustrates problems encountered where the taxonomy is poorly developed, to the extent that confusion with a distantly related parasite is possible, and host-parasite relationships are uncertain or ambiguous, or even unknown.

The CCZ-focussed studies (publication 3.4 and 3.5) provide the clearest examples of the importance of taxonomy and the challenges posed by the taxonomic impediment, but also recent advances in taxonomic work. As the CCZ is outside of national jurisdictions, it has often been beyond the immediate priority for museums (and databases) and therefore has fallen outside of earlier global harmonisation efforts. With most species from the CCZ being new to science, biodiversity is often reported through temporary names using individual taxonomic approaches and voucher collections, but not necessarily harmonised across contract areas throughout the CCZ (Rabone & Glover, 2023; Horton et al., 2024). While these may allow local-scale analyses of biodiversity, they may not meet criteria of being FAIR. This can impact syntheses and regional assessments of biodiversity and biogeography, essential for environmental management (Durden et al., 2017; Amon et al., 2022; Rabone et al., 2023a).

Structured and standardised approaches to recording and usage of these temporary taxonomic names can help address this taxonomic ‘conundrum’ (Horton et al., 2024, Rabone et al., 2023a; Rabone et al., 2023b). As part of a proposed solution, a unique identifier for a temporary name could be allocated through WoRMS with an accompanying webpage to serve as the centralising hub for the name record, with spokes out to related records on other databases (Horton et al., 2024). Such an approach meets FAIR through utilising global

database infrastructures (in this case WoRMS), and notably, requires cooperation across global data systems.

While temporary names have proliferated in the CCZ in recent years, so have formally named species, with a dramatic increase in taxonomic outputs (see Fig 2 in Rabone et al., 2023a; see also co-author works, Dahlgren et al., 2016; Drennan et al., 2021; Glover et al., 2016; Neal et al., 2023, 2022a & b; Wiklund et al., 2023, 2019, 2017; section 4.2 and Supplementary References 8.1). Publications that lay the groundwork for field guides are now emerging (Simon-Lledó et al., 2023; Bribiesca-Contreras et al., 2022; Christodoulou et al., 2022). Cooperation has advanced taxonomic efforts, as illustrated by the high taxonomic output of sampling programmes that span the contract areas (Rabone & Glover, 2023, Rabone et al., 2023a). The CCZ checklist developed in Rabone et al. (2023a) is aligned with FAIR principles, online, dynamically updatable (see Rabone et al., 2025b)<sup>25</sup>. As a regional node of WoRDSS, the World Register of Deep Sea Species (subregister of WoRMS), it is embedded within global database infrastructure, e.g. in usage of unique persistent identifiers underpinning taxa names (Vandepitte et al., 2024, 2018). This approach provides a discoverable, accessible platform for CCZ taxonomic knowledge that can be iteratively improved.

In Rabone et al. (2025a), elements of solutions to a biodiversity informatics challenge are also presented, through exploration how the SBI could work in practice. During the treaty negotiations, the SBI was proposed as a measure to support transparency in the use of MGR (of ABNJ), and to enable equitable monetary benefit sharing, thereby breaking a long-term stalemate in the treaty negotiations (Oldham & Thambisetty, 2023). Equivalent to a cruise identifier in common usage (Rabone et al., 2025a), the proposed identifier would also meet certain criteria of persistence, resolvability and global uniqueness (Page, 2023; Guralnick et al., 2015); and would be automatically generated at the point of pre-collection notification to the BBNJ Clearing House Mechanism (Article 12). It is intended to be integrated into existing biodiversity, sequence and patent databases and embedded into publications, facilitating automated retrieval (Oldham & Thambisetty, 2023). The SBI aims to trace data at the umbrella collection 'lot' level, e.g. all samples collected on a given research cruise or equivalent (Table 3, collections and biorepositories section). Specimen 'lots' generally represent bulk preserved, unsorted mixed samples and specimens, and can go unidentified and neglected for decades, partly due to the scale of the samples, but also from a lack of visibility, where researchers, even at the institute they are housed, may not be

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<sup>25</sup> <https://www.marinespecies.org/deepsea/CCZ/>

aware of them. Collections-level data descriptions are currently under development at TDWG and could be relevant here, allowing for the consolidation of “grey” specimen/collection lot-level data found outside of standard scientific literature that might otherwise remain overlooked. OBIS is also aware of the invisibility of specimen lots and exploring options to allow these data to be published (Ward Appeltans, OBIS, pers. comm.). This publication explores in detail how the SBI may be applied in practice, using real-world scenarios (Rabone et al. 2025). This novel approach to the BBNJ requirements helps to identify potential issues and explore options how they could be addressed.

### *Informatics case study 2: NTDs and lessons across disciplinary ‘divides’*

The adoption and development of biodiversity data standards like Darwin Core has been a major success as evidenced in the presented publications e.g., in mobilising occurrence data through OBIS (Rabone et al., 2023a). The NTD data landscape is more fragmented, however. A lack of findability for data on paragonimiasis in Africa necessitated a synthesis requiring considerable effort solely through the literature, given no data were available in databases (Rabone et al., 2021). Biodiversity and health communities share similar challenges (Table 3) and could be better integrated, e.g. addressed through aligned data tools, platforms data standards, and approaches, while recognising the specific differences between the fields and community needs. Increased usage of data standards and platforms like Darwin Core and GBIF by the NTD community, further development of disease-related data standards and approaches, and support and development of existing or emerging platforms provide a way forward (Table 3).

Significant advances in data handling are also evident for NTDs. The first two presented publications both highlight the need for additional spatial analysis to better understand disease transmission in schistosomiasis and paragonimiasis (Rabone et al., 2019a, 2021). In spatial tools, the disease data landscape has been highly innovative and advanced considerably, with platforms that allow visualisation and analysis of disease diversity and distributions (including landscape genetics) in dynamic platforms like Vectormap<sup>26</sup> and VectorBase<sup>27</sup> among others. Similar approaches could be applied to the deep sea, where there is a need for spatial platforms, and visualisation of genetic/genomic diversity by region, which will grow over time as genetic and genomic datasets develop (Table 3). The NTD and health research communities have also made significant advances in data collection e.g. field-based data recording on mobile phones and tablets, partly resulting from practicalities

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<sup>26</sup> <https://experience.arcgis.com/experience/5f95c3edfbea4634b8347fec0bd1dcd6/>

<sup>27</sup> <https://vectorbase.org/vectorbase/app>; <https://www.gbif.org/publisher/5db132f5-ce3f-47a3-a32b-6796c159962c>

of collecting multiple spatial, epidemiological and ecological datasets across different settings within a single research project. Timescales for the need for public health/NTD data also tend to be compressed. Data quality however remains as important as timeliness (Chiolero et al., 2023). An ideal scenario for disease data would be real-time monitoring and surveillance, combined with predictive modelling of future potential outbreaks to allow a rapid response.

At point of collection, Table 3 highlights some challenges for improving population genetic/genomic knowledge for NTDs and deep-sea species/ecosystems. A key issue for genomes from deep sea benthic organisms is time delay from collection, generally with a ROV, where a dive may span hours, with potential consequences for genome quality. However, once samples are on board, liquid nitrogen facilities on some research vessels can allow for gold-standard preservation for genomic work (Rabone et al., 2019b; Colella et al., 2021). There is a need for further R&D to optimise techniques in these settings. In general, genomic sampling for diseases like schistosomiasis present a different set of challenges. It is as crucial however, especially given widespread and wholesale mass drug administration. Without archiving of genomic samples, the potential effect of drug treatment on parasite populations (whether genetic bottlenecking and even selection for drug resistance in schistosomes, or evidence of limited impact) cannot be ascertained (Emery et al., 2025; Berger et al., 2021). Maintaining cold chain in low-income countries is potentially more challenging, but feasible. Other options include in-situ sequencing using developing technologies like Oxford Nanopore, allowing for generation of genomic data at-source.

**Table 3:** Summary of key challenges/needs and commonalities/differences across NTD-MGR-deep sea biodiversity research areas. Areas or elements of particular challenge or need for improvement are shown in *italics*. See list of acronyms for full names on pg 4.

| <b>Challenge<br/>Need/area</b>                                                               | <b>In common</b>                                              | <b>Deep-Sea/MGR</b>                                                                                                                                                                                                                                                                                        | <b>Disease/<br/>NTD</b>                                                                                                                                                                                                                                                                             | <b>Solutions/ideal<br/>outcomes</b>                                                                                                                                                                                                           |
|----------------------------------------------------------------------------------------------|---------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Taxonomy/<br>species-level<br>information                                                    | Taxonomic<br>knowledge gaps                                   | Most species<br>undescribed but<br>high diversity in<br>abyssal<br>environments,<br>Lack of taxonomic<br>expertise in<br>particular for some<br>groups;<br>Proliferation of<br>temporary names                                                                                                             | Schistosomes: lost<br>taxonomic knowledge<br>of parasites and<br>intermediate host snails<br>for schistosomiasis.<br><i>African Paragonimus-<br/>basic taxonomy,<br/>including possible<br/>undescribed parasite<br/>species and the first<br/>intermediate snail host<br/>yet to be identified</i> | Funder recognition<br>for taxonomy;<br>Temporary name<br>solutions on<br>WoRMS;<br>Increased<br>taxonomic<br>knowledge of deep-<br>sea species;<br>Better<br>understanding of<br>epidemiology of<br>NTDs                                      |
| Collections/<br>biorepositories                                                              | Funding issues                                                | <i>Collections<br/>concentrated in<br/>Global North,<br/>many bulk<br/>specimen lots &amp;<br/>specimens of new<br/>species which aren't<br/>worked on /<br/>characterised</i>                                                                                                                             | <i>Few NTD collections<br/>(SCAN a rare<br/>example);<br/>Lack of integration with<br/>biobanks/biomedical<br/>community &amp; lack of<br/>link to clinical outcomes</i>                                                                                                                            | Integration across<br>biobank/biomedical<br>& museum<br>communities;<br>TDWG collections-<br>level descriptions<br>Developing<br>collections capacity<br>in Global South;<br>Scale up co-funding                                              |
| Informatics                                                                                  | <i>Lack of data<br/>standardisation,<br/>Data integration</i> | <i>Non-digitised &amp;<br/>unstructured data at<br/>collection lot level</i>                                                                                                                                                                                                                               | Innovative mapping &<br>genetic data<br>visualisation tools &<br>platforms e.g.<br>visualising disease<br>distribution/diversity; in-<br>situ mobile data<br>recording<br><i>Technical, legal &amp;<br/>ethics challenges-<br/>patient data privacy</i>                                             | Technical<br>advances, platform<br>integration;<br>Engagement with<br>networks e.g.<br>TDWG;<br>Data harmonisation<br>& sharing                                                                                                               |
| Database<br>landscape                                                                        | OBIS/GBIF/<br>INSDC                                           | WoRMS; WoRDSS<br><br>Diverse but<br>cohesive & meets<br>community needs                                                                                                                                                                                                                                    | ESPEN, GBD, WHO,<br>WIDP; GNTD,<br>WormBase ParaSite<br><br><i>Lack of cohesion,<br/>Fragmented data<br/>ecosystem</i>                                                                                                                                                                              | Improved<br>integration in health<br>data landscape;<br>Sharing data<br>solutions across<br>health and<br>biodiversity<br>research<br>communities                                                                                             |
| Population<br>genetics,<br>genetic data /<br>Population<br>genomics,<br>reference<br>genomes | <i>Sampling and<br/>bioinformatics<br/>capacity</i>           | <i>Some genetic data<br/>but patchy coverage<br/>&amp; lack of studies-<br/>sampling<br/>challenges &amp; low<br/>species abundance<br/>in abyssal systems<br/>means sample<br/>sizes often too<br/>small;<br/>V little genomic data<br/>sampling<br/>challenges can<br/>compromise<br/>genome quality</i> | Schistosomes, many<br>population genetics<br>studies<br><i>African Paragonimus<br/>almost no genetic data,</i><br>Reference genomes for<br>schistosomes available.<br><i>African Paragonimus<br/>no genomic data</i>                                                                                | Developing<br>sampling &<br>bioinformatics<br>capacity;<br>Increased sampling<br>for both fields;<br>Integrating archiving<br>with operational<br>research for NTDs<br>& improving this for<br>deep-sea research;<br>High quality<br>genomes; |

|                                                        |                                        |                                                                                                                                  |                                                                                                                                              |                                                                                                          |
|--------------------------------------------------------|----------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
|                                                        |                                        |                                                                                                                                  |                                                                                                                                              | developing and applying new techniques                                                                   |
| Biology / ecology knowledge                            | Biological / ecological knowledge gaps | Deep-sea biodiversity, deep-sea ecology. MGR from deep-sea habitats                                                              | <i>Significance of cross-species schistosome hybrids is not clear. Paragonimus life cycle</i>                                                | Resolution of host/parasite relationships. Characterisation of deep-sea biodiversity/MGR and ecosystems  |
| Research equity                                        | <i>Challenges for both</i>             | <i>V expensive-resource intensive-concentrated in global north capacity sharing initiatives but challenges in visibility</i>     | <i>Generation of/access to genetic/genomic data – bioinformatics capacity; Challenges overall but also evidence of recent progress</i>       | Cooperation and partnership-network building; Scale up co-funding; Support for in-country led programmes |
| Funding and project – programme logistics              | Challenges for both                    | <i>Major funding streams in global north; Cruises resource &amp; planning intensive, technically challenging, long lead time</i> | Smaller funds available but more accessible; <i>Ethical approval logistics &amp; lead time challenges</i>                                    | In-country funding in Africa<br>Improved equity in funding outcomes-deep-sea research                    |
| Policy frameworks: awareness/fulfilment of commitments | <i>Awareness gaps</i>                  | <i>BBNJ lack of awareness on requirements; Not yet ratified-opportunity for improved engagement</i>                              | <i>Nagoya challenging to implement in some jurisdictions, can impede data/sample sharing &amp; wider research activities; Awareness gaps</i> | Harmonisation across UN for a in approaches to DSI, capacity sharing                                     |
| Research-policy exchange/engagement                    | <i>Challenges for both</i>             | BBNJ engagement via DOSI                                                                                                         | Good links between ministries of health/environment & operational research                                                                   | Co-production cooperation and partnership / network building<br>DOSI model for NTD community             |
| Networks                                               | TDWG, GSC, GGBN                        | DOSI, DOOS, DSBS, COBRA                                                                                                          | GSA, ISNTD, AMSTH, RSTMH, BSP, NNN, COR-NTD & others; Active networks, less policy engagement?                                               | Cross disease/health & biodiversity-networks as above                                                    |

## 5.2 Future directions and synthesis of recommendations

### *Funding for biorepositories and taxonomy*

Biorepositories provide the backbone of biodiversity and health infrastructure, and are therefore critical to evidence-based policy (Smith et al., 2022; Colella et al., 2021; Cook et al., 2020; Hope et al., 2018). Recognition of the role and importance of taxonomy and collections; underwritten by funding, is essential, as emphasised in the presented publications (Rabone et al., 2021; Rabone et al., 2019b; Rabone et al., 2023a; Rabone et al., 2023b; Rabone et al., 2025a). Better connection of the biorepository/museum and biomedical-public health communities is needed (Colella et al., 2021). This could improve not only harmonised approaches to data and sample sharing but also funding opportunities

through co-investment and partnerships. Representative taxonomic, spatial and temporal depth as well as a commitment to best practice (Rabone et al., 2019b; McLean et al., 2016) allows for collections to be adaptable and relevant for science, and society. It is important for biorepositories to have the ability to adapt and respond to emerging societal needs. For example, there is a growing urgency for new antibiotics to address a looming antimicrobial resistance crisis, estimated to claim 11M lives by 2050 (Naghavi et al., 2024). Deep-sea actinobacteria from existing and future sediment core collections hold high potential for promising lead compounds (Barbosa et al., 2020; Tortorella et al., 2018; Scobie et al., in prep). Such collections could therefore be prioritised in future MGR exploration.

### *Capacity sharing and building research equity*

Capacity sharing is a key cross-cutting theme in the presented publications, both through addressing inequity in deep sea research (Rabone et al., 2019b; Rabone et al., 2023b; Rabone et al., 2025a) and the need to improve NTD research capacity in Africa (Rabone et al., 2021) and the Global South more generally. Given the recent explosion of genomic data, it is timely now to develop frameworks and best practices, including those that emphasise equity (Fatumo et al., 2022; McCartney et al., 2023). The CARE principles: Collective Benefit, Authority to control, Responsibility and Ethics provide a complementary guiding framework to FAIR (McCartney et al. 2023). Accessibility of genomic data remains a major issue and is a limiting factor in its application both to the biodiversity crisis and public health (Hogg, 2024; Hogg & Belov, 2022). The highly specialised nature of genomic research necessitates cooperation between those generating and those utilising data (Hogg, 2024). Developing genomics capacity therefore requires concerted efforts of cooperation to achieve objectives, from point of collection through to archiving and publication (McCartney et al., 2023).

In a disease context, leadership in national health by endemic countries is crucial, for example in setting well-informed national and regional health priorities (Emery et al., 2025; Lund et al., 2022; Fatumo et al., 2022). This also applies to emerging infectious diseases and monitoring of zoonotic spillover, where lower income countries bear a disproportionate burden and experience greatest time lags between disease emergence and identification of zoonotic reservoir hosts (Colella et al., 2021). Strengthening capacity in genomics, both data generation and analysis within country are crucial for research into diseases to reduce delays between acquisition of findings and their potential application.

In contrast to the majority of terrestrial-based/inshore marine surveys, deep-sea sampling is inherently resource intensive, and demonstrates structural research inequities as a result

(Harden-Davies et al., 2022). Drivers include disparities in molecular biology and biotechnology expertise (Arnaud-Haond et al., 2011), a similar situation to NTDs, but a compounding factor is limited access to oceanographic resources including research vessels (Rabone et al., 2025a, Rogers et al., 2023). The extensive resource requirements of deep-sea research prevent most developing states (and researchers from those states) from participation, let alone leadership (Harden-Davies & Snelgrove; 2020). The deep-sea research community could draw upon lessons from NTD research where capacity sharing and engagement with policymakers (e.g., national ministries for health and the environment) is generally better established, and generally a required component of operational research projects, including as an element of funding applications (Rabone et al., 2025a; Rabone et al., 2019b; Emery et al., 2025). Active engagement with stakeholders including funders on what constitutes meaningful capacity sharing and partnership should also be conducted (Guilhon et al., 2025; Harden-Davies et al., 2022). Moreover, this approach would align with existing and emerging treaty requirements (Rabone et al., 2025a).

#### *Role of networks/boundary organisations in coproduction of science-based policy*

In the course of attending UN BBNJ negotiations and similar meetings, it has become apparent that no matter how well organised or FAIR a database, on its own, it is unlikely to influence policy. Recently there has been a reframing of the science-policy gap as a 'space', allowing for the exchange of ideas across communities (Jarvis et al., 2020; Toomey et al., 2017; Hogg, 2024), which is consistent with the idea of co-production of science policy activity. This can be facilitated by intermediaries, who act as translators of science. One such intermediary is a boundary organisation, an interdisciplinary body that sits between the 'boundary' of science, policy and society, bridging the science policy interface (Latour & van Laerhoven, 2024; Wynborn, 2015; Lidskog, 2014). Such organisations can provide the missing link between data and decision making and advance science-policy as a co-produced endeavour. In boundary organisations there is an emphasis on science-policy interaction as dynamic and collaborative (Gustafsson & Lidskog, 2018). For a boundary organisation to be effective, data and findings conveyed to policymakers should include the following characteristics: credibility (or reliability and accuracy) and relevance (for the specific policy context). A broader characteristic is legitimacy of the organisation, including fairness and inclusivity, with broad and relevant consultation with the scientific community on presented findings (Clark et al., 2016; Cash et al., 2003; Guston, 2001). Some observers have noted that the gap between science-policy has been widening over time, with contributing factors like the ever-increasing scale and complexity of genomic datasets

(Hogg, 2024; Jarvis et al., 2020). This makes the need for such organisations ever more pertinent.

An area needing specific attention and investment is the translation of science into policy (Hogg, 2024; Fatumo et al., 2022; Rabone et al., 2023b; Rabone et al., 2025a). This could involve specific training both for the science and policymaker community, including for scientists on policy engagement and vice versa, together with improved exchange between and within these communities (Rabone et al., 2025a). Mentoring early career researchers on how to engage in policy processes allows for new ideas and scientific information to enter the policy sphere with a minimum of miscommunications. Boundary organisations described above are well-placed to provide such training (Mengerink et al., 2014), which could be delivered within universities, research institutes, or similar. One example relevant to deep-sea research is the Deep Ocean Stewardship Initiative (DOSI)<sup>28</sup>, a science network actively involved in policy engagement with membership spanning 120 countries. It meets criteria of a boundary organisation: a) interdisciplinary, composed of members across science, policy, law, economics, social science among others; b) acts as an intermediary across the science-policy interface (or translator of science for policymakers); c) produces useable knowledge products- briefs, statements and recommendations; d) is well integrated into policy for a; e) has a global scope and f) supports equitable and inclusive participation. DOSI provides a model for potential future equivalents in the NTD sphere, where there are networks like GSA and ISNTD and among others (Table 3), some of which interface with WHO and ministries of health for example, but no real equivalent to DOSI at the present time.

#### *A network of regional centres of excellence in collections and research*

In global policy frameworks a trend is emerging to ‘imagine’ positive outcomes and futures to help identify elements needed to achieve these futures (Pereira et al., 2022). The third World Ocean Assessment for example aims to examine potential futures as pathways for positive development, as well as directly incorporate social science and apply interdisciplinary approaches (Rabone et al., in review). Ebi et al. (2020) identify four key characteristics for research as a priority for integrating planetary and human health: transdisciplinary, multi-scalar, inclusive and equitable, and communicated broadly. Multi-scalar approaches allow for local-regional considerations and priorities, which can unintentionally be bypassed in global frameworks (Turnhout et al., 2016).

In line with a multi-scalar approach and an emphasis on addressing global research inequities, an ideal future would see a distributed interconnected network of regional centres

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<sup>28</sup> <https://www.dosi-project.org>

of excellence in collections and research. This could be applied to both MGRs / deep sea biology and for disease / NTDs (Rabone et al., in review). Such networks could conduct relevant and timely research, achieve knowledge exchange and science-policy co-production, addressing research equity. These networks could be built from the ground up by developing in-country capacity, for example in sampling and bioinformatics, and progressing through strategic partnerships and joint funding towards building collections/repositories and research infrastructure, ultimately leading to interconnected research centres (Rabone et al., in review).

The benefits of genomic collections and research will only grow as biorepositories develop and more comparative datasets become available (Lund et al., 2022; Emery et al., in review). Training schemes for early career researchers with mentoring are an important element. Many initiatives are already underway, and in public health/disease there is recent progress in Africa, including African-led drug discovery initiatives<sup>29</sup>, and a move toward African-led and funded projects (Tsanni, 2025; Lund et al., 2022; Kyeremeh et al., 2020). But there is still a long way to go (Fatumo et al., 2022). Infrastructure development requires major initial capital funding that also needs to be sustained for maintenance and development (Collins et al., 2021). Investment should start with people however, including long-term employment opportunities. It is important to note that the cost of not investing in research and development pales in comparison of the cost of not doing so (Colella et al., 2021). Cooperation and aligned efforts will prove instrumental, leveraged through partnerships.

### **5.3 summary of recommendations**

Once challenges with data access are overcome, the next hurdle is to get science evidence to policymakers, within a range of settings, both in specific negotiations at global levels (e.g. ISA, BBNJ, CBD) but also at the national level, such as all-party parliamentary groups, political networking and NGO activities, mixed membership advisory groups and similar. Clear communication of science is a supporting factor, which entails meaningful and constructive press coverage, and wider formats such as social media and film (see section 7). To reach audiences outside of these specialised fields, it is necessary to develop lines of communication and linkages alongside programmes e.g. infrastructure development as above. This relates to ‘communicated broadly’ referenced in Ebi et al. (2020), and to recent

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<sup>29</sup> <https://h3d.uct.ac.za>

commentary that emphasises science as part of society, not separate from it (Toomey et al., 2017; Pielke, 2007).

Considering the role of global agreements and instruments, there is significant potential to leverage harmonisation efforts through the global BBNJ Agreement (Rabone et al., 2025a). The biological realities of the connectivity of marine environments mean harmonisation across legal instruments for benefit sharing of MGR and associated DSI will be necessary. The data sharing advances from the COVID pandemic provide examples for full-scale science collaboration and how some existing barriers in health research can be surmounted (Boby et al., 2023). Recommendations throughout the thesis are summarised here in brief:

- support for taxonomic/biodiversity research and archiving, emphasising cooperation with global networks, databases and initiatives accompanied by support for staff;
- recognise the critical role of boundary organisations in bridging science-policy, including in terms of training in science-policy communication;
- prioritising sharing of capacity and research equity including within funding programmes;
- develop regional centres of excellence in research and collections; both for MGRs / deep-sea biodiversity, and NTDs

## 6. CONCLUSION

In these times of ever-increasing health and environmental stressors, the need for science-informed policy is more critical than ever before. As illustrated in the preceding publications, robust policy-ready scientific information and interdisciplinary approaches can help address critical global gaps in knowledge, whether they be in deep-sea biodiversity and MGRs, or NTDs. Common elements include the importance of taxonomy and species-level data, archiving and biorepositories, harmonisation efforts for data and sample pipelines, and effective cooperation. With global genomic sampling and digitisation programmes in full swing, there is a need for meaningful coordinated efforts for data and sample standardisation, and developing research capacity, regardless of discipline. Here, global networks progress cooperation and harmonisation efforts. Discipline-specific networks can also play a key role in co-production of science-policy, acting as intermediary boundary organisations, bridging the science-policy interface with experts from both spheres. Co-production of science ideally requires integration from the start, though later partnerships are also possible, recognising science can be used to advise policy in various stages (Pelke Jr, 2007). The need for such intermediaries between science and policy is increasing, in tandem with the levels of expertise required on both sides of the equation. This thesis research has uncovered several science-policy challenges, but none were insurmountable. Rather, as illustrated in the progression of the publications, opportunities for greater cooperation and policy input continue to arise, enriching both the science and policy elements of the research. In these discussions across neglected diseases, deep-sea biodiversity and marine genetic resources, it is worthwhile to recognise there are similar challenges as well as opportunities for lessons learned, suggesting that disciplinary ‘divides’ are sometimes artificial, and also that no one size fits all (Pearson, 2024)<sup>30</sup>. This thesis has transcended disciplinary siloes and provided a unique opportunity to recognise several commonalities across these contrasting fields of research, learn lessons spanning the deep-sea-disease ‘divide’, and gain insights in the process for how science can better inform decision making. This work has achieved concrete policy impact at critical junctures, particularly in deep-sea spheres both for the BBNJ Agreement with direct input into the BBNJ process, and the ISA negotiations with initialising changes to the structure of the regulators database used by industry to report their activities. Meaningful impact is evident also for the disease studies with engagement across stakeholders and development of new collaborations from scratch. In the two very different disciplines of research examined here, similar challenges often with similar solutions were encountered, suggesting that in our seeking to connect rarified scientific knowledge with practical policies, we all may have more in common than we first realised.

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<sup>30</sup> Chagun Basha, chief policy adviser, government of India, quoted in Pearson (2024)

## **7. EPILOGUE: a personal perspective**

In my career to date, I have attempted to undertake policy-relevant, impactful science. Below is a summary of some of the lessons that I have learned along the way. This section admittedly breaks the ‘fourth wall’, a little jarringly perhaps, my apologies to the reader. Science perspectives aspire to be neutral, but being filtered through the human condition, objectivity is ultimately unobtainable (Vogt, 2013). Here, I wish to share some of what it felt like to work in research and collections and then step into the very different world of global policy development.

The CCZ studies led to a major press response across global media outlets, including with mentions on high profile shows like John Oliver, and featuring in videos by social media icons. The interview requests continue to the present day. This media attention was initially rather overwhelming. Over time, however, I learned how to manage my nerves in dealing with press attention and see it as another opportunity to disseminate science. Through it, I learned the power of metaphor and painting pictures that connect with public audiences. Deep-sea mining as a policy topic has become highly politicised, which was an eye opener. At times, I came up against questions of scientific neutrality, including internal institutional conversations on how to frame the unknown, but likely devastating, nature of the impacts of deep-sea mining operations. Clearly there was a fine line to tread.

My interactions with the media were generally positive, and I was often struck by the depth and range of questions. At times I also noticed a tendency towards over-simplification. This led me to conclude that researchers need to stay involved. It is not sufficient to deliver information, and slink back into the relative safety of the laboratory or office. Complacency can become the enemy of the consistency necessary for good science (and science-policy) communication.

My direct engagement with the BBNJ process involved delivering interventions as an observer, discussing science aspects with senior policymakers and state delegates, deliberating on messaging priorities with fellow researchers, and writing policy briefs. Clarity of messaging, and an ability to summarise and distil complex information, was a key lesson that I was not taught at university. Writing for policy audiences, and in particular, reading legal texts was like learning another language. But more than that, it felt like we, scientists and policymakers were learning each other’s languages at the same time. That was it, we were in this together.

Through this work, I experienced firsthand the responsibility that policy advising brings, including the need to simplify, but not too much. I felt a responsibility, including to those not in the room, to bring research considerations into the process, making it as objective and representative as possible (Jasanoff, 2004). That said, as one of a small handful of scientists present in these policy processes, I also felt a responsibility to speak up, to be heard. The experience taught me the value of getting involved, to be brave and engage, to trust my hunches, and learn from the process itself. I surprised myself by discovering that I had an enthusiasm, aptitude even, for science-policy engagement. It turns out in the rarefied, at times stultified atmosphere inhabited by diplomats, they can respond well to a plain-speaking scientist from outside their realm, so long as certain invisible lines are not crossed.

Through this work I also became involved as a co-producer and science advisor of a deep-sea documentary film project. 'How Deep is your Love', premiered in 2025 in the US in *True False*, and in Europe in *CPH Docs*. A fascinating process, I developed a realisation and respect for the distinct skills the entire team brought to the picture, as I had in the policy sphere. Working on this film taught me an immense amount about science storytelling and communication, in particular, clarity of message and the all-importance of narrative, whether the output is scientific, artistic, or both. Who is going to watch it? What are the stakes? What do we feel? Why do we care? How does it end? These are relevant questions, regardless of discipline. At the audience Q&A, again I was struck with the depth and breadth of public interest, spanning science, storytelling, collaboration, and policy. Public interest in the deep sea, which was previously 'out of sight, out of mind', has mushroomed, and it has been a privilege to be involved in this story. It turns out the filmmaking is not such a long walk from science, both grounded deeply in the process of careful planning, observation, and execution.

If a message does not reach, let alone resonate with an audience, it remains unconnected information rather than communication. Ebi et al. (2020), when discussing the characteristics of research to integrate human and planetary health, highlight the criterion of 'communicated broadly'. Beyond our responsibility as scientists to describe and understand the taxa, environments and ecosystems we study (and love), some of us will need to take up a further responsibility – to engage, not only with policymakers, but also the public. Otherwise, science exists in a rather lonely vacuum, with little direct societal impact.

Much of this work in the policy realm was only possible through my involvement with the Deep-Ocean Stewardship Initiative (DOSI), a large global network of deep-sea researchers. As an interdisciplinary network focussed on placing science into global policy fora, DOSI is a

good example of a 'boundary organisation' (sensu Guston, 2001). I learned firsthand the value and power of such boundary organisations, the importance of mentorship and the necessity of building relationships across disciplines to articulate a clear, balanced message. In the process, I also gained lifelong friends and colleagues.

For NTDs, there is no real DOSI equivalent, which perhaps speaks to the absence of neglected diseases in the policy sphere. Nonetheless, it has been immensely rewarding to set up a paragonimiasis project in collaboration with colleagues at NHM, Abidjan, Lambarene and Heidelberg at the grassroots level. Our recent fieldtrip to Gabon was an all-time highlight. I recognise I've been very fortunate to work in different fields of science, and different disciplines within that – data and collection management, research, and fieldwork. Being at sea also has an emotional tone little spoken of (borne of being in motion?). I've been fortunate to go on industry and publicly funded deep-sea research cruises, very different, both unforgettable. This also meant I could speak from direct experience about the conditions at sea (very distinct from the terrestrial, freshwater and inshore fieldwork I was familiar with), when reflecting and inputting on treaty requirements. Credibility and relevant experience are important elements too in science-policy interactions (Clark et al., 2016; Cash et al., 2003).

Here it is time to expand on the brief acknowledgements at the start. A special thanks to my supervisors at NHM, Aidan Emery and Adrian Glover, who always allowed me the freedom to follow my own path, without which none of this would have been possible, and for their friendship and sense of fun, always. My primary supervisor Tony Walker, together with Scott Lawton (and Aidan and Adrian) who gave me the encouragement to submit some of my published in a thesis for a PhD by Publication. My heartfelt thanks also to science-policy mentors, Jeff Ardron, Marcel Jaspars, Tammy Horton, Chris Lyal and Harriet Harden-Davies, for their steadfast friendship and support, ideas and input, and without whom I really would have been lost in choppy UN-ISA seas. Graduating from my beloved NHM basement office, shared with dear friends and colleagues Aidan Emery, Fiona Allan, Jackie Mackenzie-Dodds, Toby Landeryou, and at times Georgia Ward, for the relative glamour of a new upstairs Darwin Centre locale, I joined deep-sea colleagues Adrian Glover, Regan Drennan, Lupita Bribiesca-Contreras among others, and my indomitable officemates Sarah Jaimeson Todd, Harriet Jameson, Belen Aria and Ron Jenner. It has been an absolute privilege to work at NHM, but really, that has been all about the people. My work in science-policy has been challenging, true, and at times, plain infuriating. Would I do it all again? In a heartbeat.

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