

Managing Data in Screening Programs: Challenges and Solutions

Gerir Dados em Programas de Rastreio: Desafios e Soluções

Hugo MONTEIRO ¹, Mariana OLIVEIRA ¹, Ricardo MARTINHO ², Carlos MARTINS ³
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ABSTRACT

Population-based screening programs are vital public health initiatives that enable the early detection of diseases, significantly reducing both morbidity and healthcare costs. As these programs expand, the management of the extensive data they generate becomes increasingly complex, highlighting the need for structured digital solutions. This narrative review article presents a pragmatic framework aimed at clarifying big data analytics tailored to the needs and practices of healthcare professionals and administrators, focusing on effective integration into routine screening workflows. To achieve effective data utilization, the process begins with systematic archiving, which involves cloud-based storage solutions capable of securely maintaining various data formats in compliance with regulatory standards, thus ensuring long-term accessibility and continuity. Subsequent real-time processing of screening data facilitates rapid decision-making and patient management by providing immediate validation and analysis, essential for maintaining the responsiveness of screening services. Transformation processes play a critical role in converting diverse data inputs into standardized, consistent formats, enabling seamless communication and exchange among multiple healthcare systems. Integration further builds upon this standardization, merging data from different healthcare providers and diagnostic centers into centralized analytical platforms. This unified approach enables comprehensive patient monitoring and supports predictive modeling for early identification of at-risk individuals. Advanced analytics, particularly process mining and predictive techniques, reveal inefficiencies within screening workflows, highlighting areas needing improvement. These methods help healthcare managers to streamline operations, optimize resources, and enhance overall program performance. Real-time visualization tools provide administrators with continuous, practical insights into operational dynamics, despite existing challenges related to data governance and system interoperability. This article illustrates these concepts through concrete examples from the colorectal cancer screening program in Northern Portugal and the response to the COVID-19 pandemic. The colorectal cancer screening scenario demonstrates how structured data management significantly boosts operational efficiency and healthcare accessibility. Meanwhile, the COVID-19 experience highlights the importance of having flexible digital infrastructures capable of quickly adapting to unexpected crises. Finally, ongoing investments in digital infrastructure, professional training, and comprehensive data governance are crucial for sustaining these improvements. This review provides clear, actionable knowledge to support healthcare professionals in adopting big data analytics effectively within preventive healthcare programs.

Keywords: Big Data; Data Management; Diagnostic Screening Programs; Public Health

RESUMO

Os programas de rastreio populacional permitem a deteção precoce de doenças, contribuindo para a redução da morbilidade e custos. Contudo, à medida que ganham escala, o enorme volume e heterogeneidade dos dados exigem soluções digitais robustas. Este artigo de revisão narrativa oferece um enquadramento pragmático para a aplicação de *big data* em rastreios, adaptado às práticas clínicas e de gestão com foco na integração eficaz nos fluxos de trabalho. A utilização eficaz dos dados inicia-se com o seu arquivo sistemático em plataformas de armazenamento na nuvem, seguras e em conformidade com as normas regulamentares, capazes de preservar múltiplos formatos de informação e garantir a acessibilidade a longo prazo. O processamento em tempo real possibilita decisões céleres sobre convocatórias, confirmação de diagnósticos e triagem subsequente, mantendo a capacidade de resposta dos serviços. Os processos de extração-transformação-carregamento normalizam dados provenientes de sistemas heterogêneos, assegurando consistência semântica e interoperabilidade. Esta normalização suporta a integração de registos clínicos, laboratoriais e administrativos em repositórios analíticos digitais que se encontram centralizados, permitindo uma visão longitudinal do percurso do utente. Com esta infraestrutura, é possível agilizar técnicas de mineração de dados e de modelação preditiva que ajudam a identificar indivíduos de maior risco, antecipar picos de afluência e identificar barreiras operacionais. Estes dados apoiam a alocação de recursos e o redesenho de processos, contribuindo para ganhos de eficiência e equidade. O recurso a ferramentas de visualização interativas traduz informação complexa em relatórios dinâmicos intuitivos, facilitando a monitorização contínua de indicadores e a tomada de decisões baseadas na evidência. Persistem desafios de governação de dados, financiamento e capacitação, exigindo políticas claras, formação contínua e mecanismos de auditoria regular a estes sistemas digitais. Este artigo ilustra estes conceitos através de exemplos concretos do programa de rastreio do cancro colorretal na região Norte de Portugal. Os investimentos sustentados em infraestrutura digital, formação profissional e governação de dados são essenciais para assegurar a sustentabilidade e o impacto operacional destes programas. Esta revisão oferece orientações práticas para apoiar profissionais de saúde na adoção eficaz de análises de *big data* em iniciativas de prevenção.

Palavras-chave: Big Data; Gestão de Dados; Programas de Rastreio; Saúde Pública

INTRODUCTION

Framing the problem

Population-based screening programs are essential public health initiatives aimed at early disease detection, particularly in asymptomatic populations. By enabling timely

interventions, they significantly enhance health outcomes, reduce morbidity, and decrease long-term healthcare costs. Diseases such as cancer, diabetes, and cardiovascular conditions benefit greatly from structured screening

1. Faculdade de Medicina. Universidade do Porto. Porto, Portugal.

2. Centro de Investigação em Tecnologias e Serviços de Saúde (CINTESIS). Escola Superior de Tecnologia e Gestão. Instituto Politécnico de Leiria. Leiria, Portugal.

3. Centro de Investigação em Tecnologias e Serviços de Saúde (CINTESIS@RISE). Universidade do Porto. Porto, Portugal.

✉ **Autor correspondente:** Hugo Monteiro. hugo.filipe.b.monteiro@gmail.com

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For healthcare professionals, understanding these concepts is no longer optional. They underpin the technologies that now influence everything from triage to follow-up scheduling. Tools like predictive analytics can flag patients at higher risk and prompt timely actions. Meanwhile, process mining techniques optimize workflow efficiency, reduce delays in patient follow-ups and resource allocations.¹² Advanced computational statistical models, including machine learning (ML) and artificial intelligence (AI), further enhance the capacity to uncover actionable patterns, refine protocols and improve program outcomes.^{13,14}

However, the transition to big data-driven infrastructure does not come without challenges and requires more than access to software. It requires an alignment between data systems and clinical practice, ensuring that tools support – not replace – professional judgement. Therefore, integrating diverse data sources requires adherence to standardized data models.¹⁵ Privacy regulations such as the General Data Protection Regulation (GDPR) introduce stringent requirements to safeguard sensitive health information. Furthermore, while advanced analytic methods hold promises, they must also address potential biases and maintain transparency to ensure patient trust and equity in healthcare delivery.¹⁶

To address these challenges, screening programs must implement structured, data-driven strategies that prioritize security, interoperability, and analytical rigor. Digital platforms play a key role in supporting the various needs of screening programs, including:

- Clinical needs: Facilitating patient care through EHRs and decision support systems.¹⁷
- Administrative needs: Optimizing scheduling, resource allocation, and reporting.¹⁸
- Process monitoring needs: Tracking workflow efficiency and program performance.¹⁹
- Data management: Ensuring data quality, security, and compliance with regulatory standards.²⁰
- Financial oversight: Managing costs, billing, and financial analytics.²¹

By leveraging these principles in everyday operational realities, screening programs can improve operational efficiency, enhance equity in healthcare access, and maximize the impact of preventive interventions.¹⁴ Drawing on lessons from Portugal's colorectal cancer screening program, this narrative review aimed to synthesize recent evidence and practice-based insights into a five-phase data management framework that can strengthen preventive medicine services. Colorectal cancer remains one of the leading causes of cancer death in Europe, presenting the need for robust screening strategies supported by effective digital systems. We present a practical overview of big data integration in real-world screening programs, highlighting both the per-

sistent barriers and the solutions that have contributed to sustainable, outcome-oriented models.²²

Handling data

To overcome the data management challenges of modern screening programs, we propose a structured, five-phase framework (archiving, processing, transformation, integration, analytics – Fig. 2) capable of addressing the unique challenges posed by the nature of this data.³ In the following sections, we detail how each phase contributes to building resilient, interoperable, and insight-driven screening programs – drawing from real-world implementations in Northern Portugal.

Archiving: ensuring data longevity and compliance

Effective long-term data storage is critical for screening programs, as data must be retained for patient follow-ups, epidemiological studies, and quality control processes. Given the scale of these programs, traditional storage methods are insufficient, requiring cloud-based solutions that provide scalability, redundancy, and compliance with data protection regulations such as GDPR. Screening data often spans a wide range of formats, including structured EHRs, unstructured imaging files, and laboratory tests, all of which require tailored storage solutions. Modern storage solutions, such as cloud-based infrastructures, can enhance data accessibility and scalability. These systems should incorporate role-based access permissions and embedded security protocols to ensure compliance with confidentiality standards and data protection regulations.²³

One of the persistent challenges in data archiving is managing legacy systems. Older databases were often designed without significant future expansions in mind, leading to difficulties when integrating with modern digital platforms. Additionally, storage costs increase over time, especially as screening programs expand their reach and generate more data, including high-resolution medical imaging.²⁴ Screening data in our experience grew from just a few megabytes per month to over dozens of GB within five years – making cloud scalability a non-negotiable requirement.

Addressing these challenges requires initiative-taking budget planning for storage infrastructure, periodic system upgrades, and interoperability frameworks that allow seamless data retrieval from both old and new systems.

Real-time processing: unlocking insights and enhancing efficiency

Timely data processing is a critical requirement in screening workflows, where delays in analyzing test results can impact early intervention efforts. Screening data flows continuously, from appointments to test results, which requires immediate validation and feedback loops.²⁵

enabling patient monitoring, performance evaluation, and predictive insights. Population-wide programs rely on integration to combine data from hospitals, labs, registries, and administrative platforms. Integration efforts ensure that screening data is not siloed and simply stored but rather accessible for holistic patient monitoring, predictive modeling, and program evaluation. Data from more than 30 institutions was consolidated and connected daily, changing reporting lags from weeks to minutes, making it possible to monitor thousands of different processes close to real time.

To achieve this, data lakes and relational databases should be used to store and unify data, allowing healthcare providers to retrieve both individual patient records and aggregated population-level insights. Additionally, data connectors are deployed to enable automated merging of screening data across multiple platforms, minimizing the need for manual reconciliation. These connectors facilitate cross-institutional interoperability.

However, integration presents challenges, particularly when connecting digital systems that rely on different technical standards. Numerous systems, including database management systems (DBMS), use proprietary protocols and data structures, thus making data exchange intricate and time-consuming. For example, differences between structured databases (such as those using SQL) and more common file formats like spreadsheets often require additional steps to align and prepare the data. Technical mismatches caused delays, errors, and duplications, slowing down analytics pipelines.

Analytics: unlocking actionable insights

The goal of screening data management is to extract valuable insights that improve program efficiency and patient outcomes. Process mining techniques are particularly useful in screening programs, as they allow managers to identify inefficiencies in operational workflows, such as delays in test processing, scheduling gaps, or bottlenecks in follow-up procedures.³⁰ Tools like Power BI,³¹ MicroStrategy,³² and R³³/Python³⁴-based dashboards enable healthcare administrators to monitor screening program performance dynamically.

Several challenges persist despite these advancements. The absence of clear application programming interface (API) integrations, standardized data governance policies, and well-defined analytical workflows often delay the implementation of advanced solutions. Additionally, the risk of biases in machine learning models must be carefully managed to prevent disparities in screening access and outcomes. Lastly, the effectiveness of data-driven insights is dependent on high-quality, clean, and well-structured datasets, which remain a significant challenge in real-world healthcare environments.

By following the principles described above, we will provide evidence of the experience of the implementation of such techniques in screening programs and solutions found in alignment with best practices.³⁵

Lessons learned: data-driven health interventions

In the northern region of Portugal, screening programs were implemented using the discussed methods. These programs covered most of the eligible population over more than ten years and included both oncological and non-oncological areas.

Data archiving and storage challenges

Archiving has played a critical role since the inception and evaluation of screening programs. However, legacy systems have struggled to scale effectively, leading to bottlenecks as screening volumes increased. Initially, available server storage seemed sufficient. However, as the screening program expanded, growing storage needs and renewed processing demands underscored the need for strategic planning in acquiring more robust digital systems.

However, legacy databases posed difficulties in retrieval and integration due to outdated formats and limited compatibility with modern digital platforms. Solutions included targeted infrastructure upgrades and interoperability frameworks to bridge gaps with legacy databases.

Data integration and standardization

Digital platforms have facilitated the expansion of local implementations to broader populations by standardizing data processes and enhancing transparency. Real-time dashboards provide regional health program managers with immediate insights into underperforming areas, allowing targeted interventions to boost screening uptake.

A major challenge (Table 1) in data integration stemmed from disparate DBMS, inconsistent protocols, and variations in language formats and file structures. Lack of clear connectors to data forced manual data reviews, slowing issue detection and requiring high technical expertise. Overcoming these obstacles required continuous standardization efforts and signaled the need to accelerate the adoption of interoperability frameworks such as HL7 and FHIR.

Nevertheless, these platforms also supported the automation of routine processes, freeing up resources for strategic tasks and enabling faster deployment of updated workflows, providing more time to audit processes, replying to queries from local program coordinators or other healthcare professionals and even providing the opportunity to innovate. To provide a concrete figure, automating data collection of eligible patients can represent a task taking weeks to less than a few hours or even minutes. This enabled more accurate cost analysis and adjustments, ensuring

Table 1 – Summary of key challenges encountered in big data management for screening programs and the solutions implemented to address them

Concepts	Challenges in big data management	Experience
Archiving	Considering the volume of patients by the millions per year, multiple data sources are stored across servers in a widely distributed area.	It is required to define the format of data being stored; the size of the files (image files to be attached to reports can be sized by Gb or Tb); and additional budgeting might be required as technology improves not only in terms of the size of the software programs but also record size.
Processing	Servers dedicated to various aspects of data processing, as well as for image rendering, may be necessary.	If thousands of healthcare professionals work in multiple places and see patients every day, or if tests are performed daily, queries to the database to check administrative identification or validate past values are a constant.
Transformation	Primary data might be stored in wide table formats, or secondary data be the result of table merging during processing - to match records with new test results.	This requires a middle layer of specific processing to guarantee that data quality is assessed and that data values comply to regulatory standards. Indicators are also processed in this stage, where granular data is aggregated and computed to simplify signals or provide visual alerts.
Integration (connectors)	To view data from its multiple sources, where data is stored, and to transform data and provide the possibility of analyzing it, data must be integrated into a middle layer dedicated to the creation of semantic models.	Connectors from different DBMS are not mapped or established in protocols, this means that certain loaded files show differences in language formatting or type (e.g., .xls versus .xlsx) which delays the data handling process.
Analytics	Data Science is an end and a window to all the processes related to data. The abstraction of data into understandable concepts produces information and knowledge	Due to the lack of clear API and User profiles, mapped entities, or standard data protocols to ensure quality, analytics is a “delayed” product. Where it is easier to provide descriptive analysis, and more advanced methods lack timely usefulness.

resource allocation closely matched demand, thereby avoiding overspending or underspending. These operational improvements, combined with standardized data pipelines, automation of routine processes, and structured training for key users improve capacity in scaling the framework across diverse institutional settings.

Advanced analytics and data utilization

Advanced analytics enabled descriptive, comparative, and scenario-based analysis, helping transform raw data into strategic decisions. Tools like Power BI allowed managers to explore large datasets and deliver tailored insights (example of dynamic dashboards presented in Fig. 2). For instance, visualizations of patient journeys helped identify drop-outs in screening adherence, allowing targeted outreach to improve follow-up rates.

Furthermore, process mining techniques revealed workflow bottlenecks and reduced operational delays through timely alerts and resource reallocation. This capacity to identify bottlenecks helped reduce the number of operational delays by facilitating timely adjustments in response to workflow dynamics. For example, whenever unexpected disruptions to services were detected, different resources responsible for ‘upstream’ or ‘downstream’ activities could

be warned of the delays and adjust accordingly.

The robust data ecosystem also enabled more equitable access to healthcare services. Vulnerable populations, previously underrepresented, were provided free-of-cost screening tests, diagnostics, and treatment plans through the National Health System, supplemented by private care procurement agreements. By leveraging these tools and strategies, program managers ensured that the entire eligible population was included within a span of less than three years for each screening program. This comprehensive inclusion significantly enhanced the accessibility and impact of screening services, particularly in underserved regions.

Response capacity during COVID-19 and inclusive program maintenance

The adaptability of digital platforms proved essential in maintaining screening continuity during the COVID-19 pandemic. The ability to rapidly analyze large datasets and modify workflows ensured service resilience. The crisis exposed gaps in integration and coordination, reinforcing the need for interoperable, crisis-resilient systems. At the onset of the pandemic, disruptions to routine appointments and diagnostic follow-ups threatened to stall screening activities. Yet, digital infrastructure – equipped with centralized

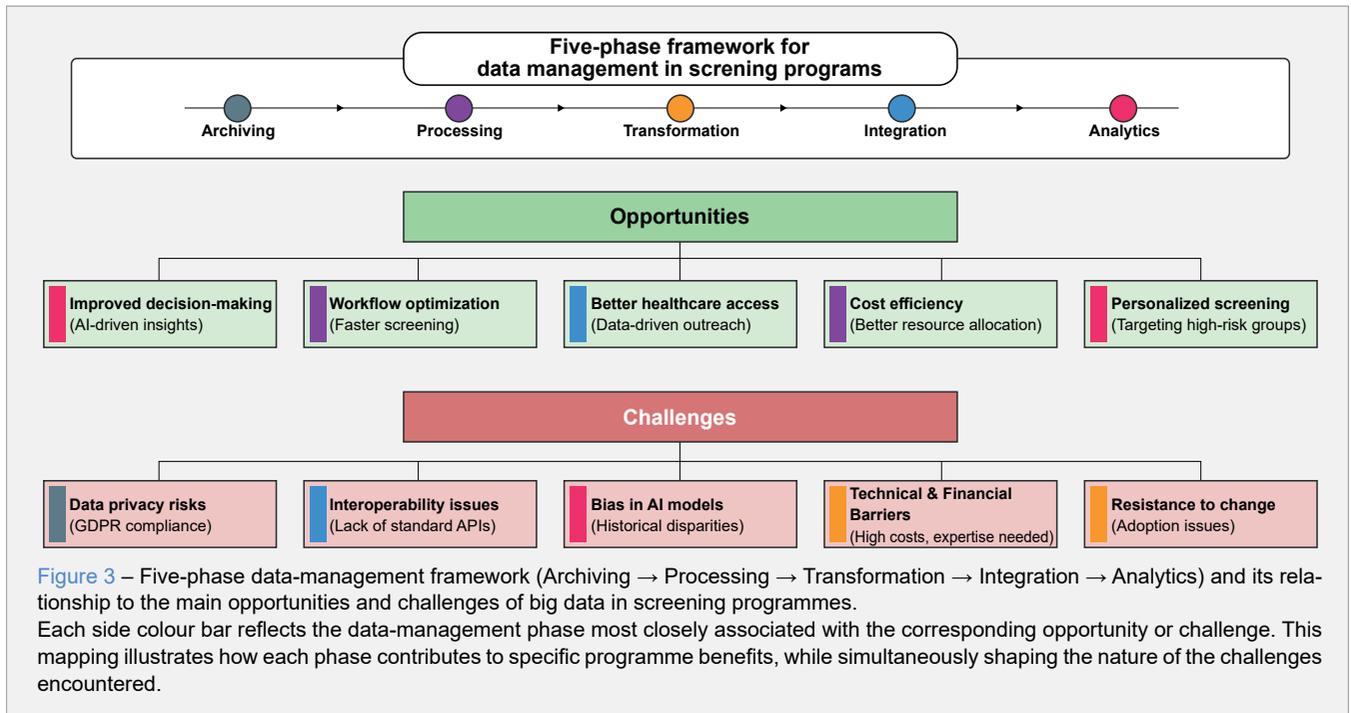


Figure 3 – Five-phase data-management framework (Archiving → Processing → Transformation → Integration → Analytics) and its relationship to the main opportunities and challenges of big data in screening programmes. Each side colour bar reflects the data-management phase most closely associated with the corresponding opportunity or challenge. This mapping illustrates how each phase contributes to specific programme benefits, while simultaneously shaping the nature of the challenges encountered.

dashboards and automated data connectors – helped re-schedule and reorganize screening appointments with minimal delays. Real-time dashboards helped coordinators detect service gaps and adjust schedules, avoiding prolonged care delays.

The pandemic experience reinforced that flexible data architectures, continuous workflow auditing, and stakeholder collaboration are key components in sustaining screening effectiveness under extreme circumstances. Going forward, building crisis-resilient infrastructure and workflows, with these tools and application of the concepts presented in this paper, will be instrumental for protecting public health and minimizing disruptions to essential services, even beyond COVID-19.

Training and capacity building for digital platforms

Even with strong digital platforms, success hinged on training healthcare professionals to use them effectively. Training programs were developed to enhance user proficiency in handling screening management tools and business intelligence (BI) dashboards.³⁶ Business intelligence tools had to be adapted to different user needs, from clinical staff to regional managers. Providing structured training sessions helped bridge digital skill gaps, ensuring seamless adoption and use of these technologies. Structured training, aligned to user roles, helped balance depth with practicality. Based on user profile and providing key users with the capacity to train others was essential to scale up faster digital platform usage.

Data driven screening programs

Big data strategies significantly improved efficiency, responsiveness, and equity in screening programs. However, the transition from traditional data handling to advanced digital ecosystems is not without challenges (Fig. 2), particularly in the context of critical healthcare scenarios where rapid adaptability is essential. Often, barriers such as limited funding and digital skills, not the technology itself, hinder implementation. This highlights the need for targeted investments in capacity-building and digital literacy.³⁷

By integrating real-time dashboards, program managers could identify underperforming areas and bottlenecks, implementing targeted interventions with minimal delay. For instance, during periods of increased demand, such as flu seasons or post-pandemic recovery, quick access to updated data prevented the system from becoming overwhelmed, allowing for adequate distribution of resources. However, reliance on digital tools introduces vulnerabilities, including potential system downtimes, data input errors, and risks related to data integrity. Implementing strong data governance frameworks and redundancy measures is critical to mitigating these risks. Furthermore, privacy concerns and compliance with regulations like GDPR add layers of complexity, particularly in the context of cross-platform data sharing. Balancing transparency with data security remains a delicate and ongoing challenge.

Another key area of discussion is equitable access. Results show that big data tools enabled significant improvements in reaching underserved populations. This raises the

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authorized institutional datasets. All procedures complied with legal regulations and were approved by the Health Ethics Committee of the Regional Health Administration of Northern Portugal (CE/2023/96).

DATA CONFIDENTIALITY

The authors declare having followed the protocols in use at their working center regarding patients' data publication.

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CONFLICTS OF INTEREST

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